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COPING WITH CANCER TREATMENT: OVARIAN CANCER PATIENTS' EXPERIENCE OF CHEMOTHERAPY

by

DEBRA DAWN McDOUGALL

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

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OF MASTER IN EDUCATION

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

SPRING, 1987

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled COPING WITH CANCER TREATMENT: OVARIAN CANCER PATIENTS' EXPERIENCE OF CHEMOTHERAPY submitted by Debra Dawn McDougall in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION in COUNSELLING PSYCHOLOGY.

..Rowena Tymchuk.....

Supervisor

.Robert Fowler.....

Marvin Allen.....

Date ..April..15./.1982

Dedication

To Tara Rae McGrath

- the new chapter in my life -

Abstract

The purpose of the present investigation was to gain an understanding of ovarian cancer patients' experience of illness and chemotherapy treatment and to determine the coping strategies they utilized during the treatment process. The design was qualitative in nature, focusing on the patients' perspective of their situation.

Four representative informants were selected from those ovarian cancer patients receiving a chemotherapy treatment protocol including cis-platinum. Two of them were just beginning their course of treatment, one was in the middle, and one was at the end of her current chemotherapy series.

Informants were each observed and interviewed four times, twice at home and twice at the treatment center. Semi-structured interviews were conducted to elicit the patients' perspective regarding three general research questions: 1. How do ovarian cancer patients experience their treatment? 2. How do ovarian cancer patients receiving chemotherapy perceive their treatment? 3. What coping strategies do ovarian cancer patients currently utilize to cope with their illness and treatment?

Two integrative themes emerged from analysis of interview and observation data. These were patients' descriptions of their experience as one of 'biding time' and as 'negative but tolerable'. In addition, six inter-related categories were derived. These were support, physical response, emotional response, coping strategies,

treatment expectations, and learning about diagnosis. Further subdivisions were also identified.

Findings of the present study were consistent with those in the current literature that suggest that chemotherapy negatively influences the quality of patients' lives (McArdle et al., 1981; Meyerowitz, Sparks, and Spears, 1979). Levels of subjective distress varied considerably among informants. They employed a number of coping strategies that appeared to enable them to manage their situation and indicated a general willingness to tolerate the negative effects of treatment in order to realize the potential therapeutic benefits.

The need for further validative research in this area was emphasized and implications for future research and clinical practice were proposed.

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Thesis-writing is often a lonely task but one that could never be accomplished alone. I would like to acknowledge some of the many people who have helped me through the experience.

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CHAPTER I

INTRODUCTION

Introduction to the Study

Significant gains have been made in recent years in the development of effective cancer treatment regimens. Advances in diagnostic measures, surgical techniques, radiation therapy, and chemotherapy have resulted in disease remission and improved prognosis for cancer patients (Carter, Glatstein, and Livingston, 1982, p. 629). DeVita and associates have stated that approximately 40-50 percent of cancers are curable (cited in Singer, 1984, p. 2304). In cases of advanced metastatic disease where cure is not possible, prolonged survival is often achieved through aggressive multimodal intervention. Patients who, in the past, would have been told that "nothing could be done", now frequently undergo an extended course of treatment and face the possibility of surviving much longer than could have been expected a decade ago. As Weisman (1979, p. 13) noted, "The diagnosis of cancer is no longer an automatic death sentence...it spreads into social and emotional domains as patients must cope with treatment that is both prolonged and uncertain".

Unfortunately, adverse physiological and psychological side effects associated with many current treatment protocols can compound the stress in an already compromised system and have a negative impact on an individual's quality of life. The treatment itself can create distressing symptoms such as anemia, hair loss,

decreased immunity to disease, diarrhea, anorexia, stomatitis, nausea, vomiting, and depression (Golden, 1979, pp. 285-293). This paradoxical situation whereby the "solution" causes additional problems poses a particular challenge to both patients and the health care team. Some patients are unable to tolerate the adverse side effects and choose to discontinue treatment (Whitehead, 1982, p. 200; McArdle et al., 1981, p. 262). Others cope very well with the treatment and are only minimally disrupted by side effects. It would appear that there is a "human factor" that plays a role in patients' response to and ability to cope with their illness and treatment. Although individual differences in physiological make-up are important factors, it is recognized by patients and health care personnel alike that psychological strengths and vulnerabilities play a role in one's ability to cope with the treatment.

Background to the Problem

Ovarian cancer is increasing in incidence among industrialized populations and is one of the most common cancers in North American women. While accounting for approximately 25 percent of all gynecologic cancer it is the leading cause of death among those suffering from genital malignancies (Cancer Facts and Figures, 1985). There are usually no early manifestations of ovarian cancer and it is, thus, difficult to diagnose. At the time of initial diagnosis approximately 60 to 70 percent of malignancies involve metastases outside the ovaries

(Barber, 1979, p. 341; 1986, p. 149).

Surgery is the most effective primary treatment for ovarian cancer and typically involves removal of the uterus and both ovaries (Hubbard, 1978, p. 117; Thigpen, 1985, p.9). Following surgery, patients with advanced disease generally receive a course of chemotherapy. A "second look" surgery is usually performed following chemotherapy to determine disease status and plan further treatment (Eustace, 1980, p. 377; Smith, 1985, p. 13).

Although a wide range of agents have been determined to have some activity in the treatment of ovarian carcinoma, combination chemotherapy protocols including platinum compounds have been found to have the most impressive response rates and represent the current treatment of choice for most ovarian cancer patients (MacLean, 1986). Unfortunately, side effects of combination chemotherapy include severe nausea and vomiting as well as possible renal, cardiac, and hematologic toxicity for which the patient must be closely monitored (Barber, 1980, p. 9). Recent advances in antiemetic therapy have resulted in improved symptom control, however, resulting in increased tolerance of the drugs as well as greater comfort and improved outlook for patients (McLean, 1986). Despite these promising gains, however, it remains that the course of illness and treatment for these women is uncertain and arduous.

Statement of the Problem

Although aggressive chemotherapy is physically, emotionally, and socially stressful, relatively little research has been undertaken to gain an understanding of its psychosocial impact on patients. Attention has been paid to the complications associated with chemotherapy, particularly the negative side effects, but few efforts have been made to examine the patients' view of treatment. Those studies that have addressed psychosocial issues have focused primarily on the experiences of breast cancer patients (Derogatis, Abeloff, & Melisaratos, 1979; Hughson & Cooper, 1983; McArdle et al., 1981; Meyerowitz, Sparks, & Spears, 1979). The findings have consistently indicated that adjuvant chemotherapy treatment negatively influences the quality of patients' lives, causing emotional distress as well as impaired relationships and activity levels. Among the patients themselves there is wide variability in the patterns of responding to the negative aspects of treatment ranging from "quiet endurance" to discontinuation of treatment (Meyerowitz et al., 1979, p. 1616).

The purpose of this study was to learn about the patients' view of their experience of aggressive cancer chemotherapy and to determine the coping strategies used during the treatment process.

Importance of the Study

Further exploratory research is needed to extend our knowledge of the experience of chemotherapy patients. This

need was emphasized in a survey of 575 nurses who indicated that the determination of effective methods for relieving radiation and chemotherapy-related nausea and vomiting should be the number one priority for nursing research (Oberst, 1978, p. 285). Recent conferences of the National Institute of Health have also stressed the critical need for research addressing the psychosocial impact of chemotherapy (Check, 1980, p. 1085; National Institute of Health, 1986). This research is necessary in order to ascertain what patients themselves consider to be most important during their chemotherapy experience, and what strategies they currently employ to cope with the stress of their illness and its treatment. Further information will help identify areas of concern and ultimately assist health care personnel to provide more effective care for patients on chemotherapy.

There have, to date, been no systematic studies of ovarian cancer patients on chemotherapy. In light of the increasing incidence of ovarian cancer, its high mortality rate, and the growing number of ovarian cancer patients receiving aggressive chemotherapy, it is imperative that research be directed at gaining understanding of this particular group. Also, as methods of treatment improve patients expectations for extended survival, new issues related to prolonged therapy and variable response to treatment arise. Additional emphasis on the need for investigation in this area was provided by nursing staff of

the Day Care Unit, Cross Cancer Institute who identified ovarian cancer patients receiving cis-platinum as a significant management challenge (Donnelly, 1985). It was felt that a preliminary study of patients' experience from the patients' perspective would be an important forerunner to the planning and implementation of nursing and/or psychological interventions.

Research Questions

The following research questions were investigated:

1. How do ovarian cancer patients experience their treatment? That is, what does it feel like, physically and emotionally, to be receiving aggressive anti-cancer drugs?
2. How do ovarian cancer patients receiving chemotherapy perceive their treatment? That is, what do they think about their treatment and how do they conceptualize it?
3. What coping strategies do ovarian cancer patients currently utilize to cope with their illness and treatment? What is their perception regarding the effectiveness of these strategies?

This research has both theoretical and practical significance in extending the knowledge base of health care providers and directing them toward appropriate interventions.

Scope and Limitations of the Study

Qualitative investigation was determined to be the most appropriate methodology by which to examine this research problem. That is, it is a problem concerned with

gaining understanding of "meaning" and "experience" rather than predicting relationships between variables and testing hypotheses. The goal was to obtain rich, subjective data that would promote increased understanding of what it feels like to be on aggressive chemotherapy. The problem was process rather than outcome-oriented.

Further support for qualitative examination of the problem arose from the fact that, at this time, there is no comprehensive body of knowledge that identifies the important variables in the area. Although there has been a recent proliferation of questionnaires, scales, and indices designed to assess patients' physical symptoms, emotional status, and coping strategies, efforts to standardize the instruments on cancer populations have been limited (Leigh, Feinstein, & Reiser, 1980; Folkman & Lazarus, 1982; Jalowiec, Murphy, & Powers, 1984; Zung, 1983). Also, it is unclear whether these assessment tools are addressing the appropriate questions or whether they are promoting a narrow and biased perspective. For example, administrataion of the Pain and Distress Scale (Zung, 1983) may lead to increased awareness of the number and nature of specific problems but does little to promote understanding of the patients' actual experience of distress. In this regard, traditional methods have been criticized for tempting researchers to restrict the focus of their interest and for leading to "methods determining the problem investigated rather than the other way around"

(Mishler, 1979, p. 7).

Qualitative methodology allows for a theory development whereby questions and hypotheses arise out of the data collected rather than direct the data-collecting process. Within this methodological framework, previous research is used as a guide to the investigation but does not restrict the focus of analysis by trying to fit the data presented into a predetermined 'reality' (Field & Morse, 1985, p. 34). That is, the categories presented in the following report arose from the data offered by the informants not from analyses previously presented in the literature.

It was recognized from the outset that adopting this particular methodology would limit the generalizability of the findings to other settings. Generalizability, in the conventional sense, was not the goal of the study, however. Rather, the purpose was to gain an understanding of the patients' experience of chemotherapy. Relevance of the findings beyond this particular sample comes from the possibility that the data might yield statements describing universal social processes.

Definition of Terms

The present study aims to explore the experience of illness and treatment from the patient's perspective. Within this broad question, issues related to patients' patterns of coping are examined. Chapter II discusses various theoretical positions in the area of coping but

given the diversity of definitions and conceptualizations it seems important at this time to specify the definition that served as a guide for the present investigation.

The comprehensive definition and description of the coping process put forward by Lazarus and his associates (1984) was determined to provide the most appropriate guide for analysis of the data from the present investigation. They define coping as "the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 283).

Overview of the Present Thesis

Chapter I of the thesis has presented a statement of the problem addressed by the present. The importance of the research question and the need for qualitative investigation in the area was discussed. The research questions were stated and the scope of the current study was outlined.

Chapter II examines related literature in the area of psychosocial oncology. The conceptual framework of stress and coping is presented as a useful basis from which to explore cancer patients' experience of chemotherapy treatment.

Chapter III details how the study was conducted. Methods of sample selection and procedures of data collection are described. The evolving nature of qualitative methodology is discussed.

Chapter IV presents the findings of the study. The categories and themes that emerged from the data are defined and enhanced with quotes from interview text.

Chapter V discusses the clinical and research implications of the study. Questions and hypotheses arising from the current investigation are presented and recommendations for further research and clinical interventions in the area are made.

CHAPTER II

SOME RELATED LITERATURE

Introduction

Continued improvement in biomedical management of cancer has been the major focus of oncology research this century. As advances in early diagnostic measures and treatment regimes improve patients' long-term outlook in terms of survival, they are confronted with new issues related to chronicity and face the possibility of an extended course of treatment, repeated tests and surgeries, and an alteration of previous activities and lifestyle. There is little question that the diagnosis of cancer and the treatment that subsequently follows diagnosis impose a great deal of stress on individuals and their families.

Attention to psychosocial aspects of cancer care has, in the past, typically included promotion of public awareness of early warning signals and provision of support to patients and their families in the terminal phase of illness (Holland, 1984, p. 2218). Recently however, there have been research efforts aimed at gaining a better understanding of the social and emotional impact of cancer and its treatment. The importance of this shift was emphasized in Ware's (1984, p. 2307) assertion that "there is more to life than not dying". That is, it is being recognized that the scope of research and clinical work must broaden to include exploration of psychosocial as well as biomedical management of cancer and consideration of the

impact of treatment.

In this chapter a review of literature pertinent to patients' response to cancer and its treatment is presented. Firstly, methodological considerations are addressed and rationale for further qualitative investigation in the area is provided. Secondly, specific issues related to demographics, diagnosis, and treatment of ovarian cancer are presented to provide information regarding some of the unique issues faced by this group of patients. Thirdly, although there have been no systematic investigations of ovarian cancer patients' psychological responses to illness and treatment there have been a number of studies exploring a variety of psychosocial variables among both general cancer populations and specific sub-groups such as those with breast or lung malignancies. Though limited in terms of generalizability to the specific target group, results of these efforts are clearly relevant to the present investigation and are reviewed under the major heading of Impact of Illness and Treatment. Fourthly, the conceptual framework of stress and coping is recognized as providing a useful basis from which to explore cancer patients' experience of illness and treatment. It emphasizes the need to gain an understanding of how patients view their current situation as well as how they see themselves acting on or "coping with" their stress. The discussion highlights some of the current theoretical perspectives and issues in the coping

literature and emphasizes the importance of incorporating knowledge from the study of non-clinical populations with the increasing body of information related to specific cancer groups. Finally, a summary and critique of those studies assessing coping among particular cancer populations is presented.

The major headings in Chapter II are Methodological Considerations; Ovarian Cancer: Demographics, Clinical Course, and Treatment; Impact of Illness and Treatment; Coping Theory; Coping Strategies; and Conclusion.

Methodological Considerations

Recent proliferation of research into psychosocial issues related to coping with cancer may be reflective of a trend toward viewing patients from a more holistic perspective. There appears to be growing recognition that in order to optimize the effectiveness of health care interventions attention must be paid to the psychological and social needs of patients as well as to their physical problems. This was emphasized at a recent development conference of The National Institute of Health (1986) where it was recommended that future research consider psychosocial as well as physiological implications of adjuvant chemotherapy. Specific suggestions included assessment of the psychological, social, and economic impact of chemotherapy as well as exploration of better methods to control its side effects (p. 47).

Further research in psychosocial oncology is necessary

in order to identify and clarify the important issues and to plan appropriate psychosocial interventions. The most appropriate and efficient way by which to proceed with the task of extending knowledge in the area has yet to be agreed upon, however, and the result is a myriad of studies whose overall purpose is not clearly defined. The importance of developing a comprehensive psychosocial theory was underscored by Siegel (1983). She stated that this theory should be based on a sequential progression of research studies beginning at the earliest stages with descriptive studies sparked by clinical insights, leading to correlational research, and finally to predictive studies (p. 101).

Unfortunately, this smooth progression does not appear to have taken place in the field of psychosocial oncology. What the literature does reflect is an abundance of correlational and predictive studies and a dearth of systematic qualitative investigation. Indeed, a great proportion of attention is directed toward determining the most appropriate assessment tools and discussing whether standardized or population-specific measurement devices are superior.

In this regard, Bloom and Ross (1982) discuss some of the advantages and disadvantages associated with the use of standardized instruments to assess psychosocial functioning among cancer patients. They note that psychometrically superior instruments such as the Minnesota Multiphasic

Personality Inventory (MMPI) or the 16 Personality Factor (16 PF) may be inappropriate for use with cancer patients. For example, questions assessing depression consider decreased appetite and energy level. These symptoms are commonly associated with cancer and its treatment and do not necessarily reflect psychopathology. In addition, they noted that patients with physical problems often resent being asked to complete long psychological inventories that seem to be looking for psychopathology (p. 269). Others have also criticized the practice of assessing a cancer population with instruments designed to follow normal or mentally ill patients (Yates and Edwards, 1984, p. 2377; Spinetta, 1984, p. 2222).

Bloom (1984) has advocated the use of specific rather than standardized measurements to assess the psychosocial functioning of cancer patients. In addition, she emphasized that any measurement model must include understanding of the subjective experience of the cancer patient (p. 2326). Several researchers have been involved in developing and evaluating instruments specifically for use with cancer populations.

Worden (1983) designed a screening instrument to identify newly diagnosed cancer patients at risk for developing emotional problems. This assessment provided a basis for the provision of psychological support and intervention directed toward the high risk group. A somewhat similar instrument consisting of a structured

problem-oriented interview was developeded by Freidenbergs, Gordon, Hibbard, and Diller (1980) to determine cancer-related psychosocial problems. Psychosocial interventions were based on the results of the assessment.

The Cancer Inventory of Problem Situations (CIPS) was specifically designed to document day-to-day problems experienced by cancer patients (Schag, Heinrich, & Ganz, 1983). The researchers evaluated the instrument on 84 patients and found that they experienced moderate to severe problems in personal care, activity management, involvement with the health care system, work, and interpersonal interactions (Heinrich, Schag & Ganz, 1984, p. 979). No effort was made to examine the degree of distress associated with these problems or to understand the patients' subjective experience, however.

Expanding the discussion to include methodological issues in the study of coping it can be seen that there is a similar emphasis on the development of instrumentation. Singer's (1984) review outlines 14 scales designed to measure coping and describes the nature of the assessment as well as the target populations for each instrument (p. 2311). In addition, he points out the difficulties that arise from the lack of consensus regarding operational definitions of many concepts and ways of asssessing certain variables. For example, drinking alcohol is described by some as a passive coping strategy. Others classify it as taking action. Similarly, denial is defined differently by

different researchers. Thus, it can be seen that coping responses could be classified differently depending on the theoretical orientation of the researcher (p. 2309).

Systematic investigation of individuals' experiences from their own point of view eliminates this potential for error resulting from discrepant definitions. Colaizzi (1978, p. 57) supports this approach and encourages investigators to begin by "contacting the phenomena as people experience it". He cautions against entering into a study relying entirely upon *a priori* operational definitions because these definitions "eliminate the phenomenon's experiential aspects". Haan (1982) also supports naturalistic research and notes that although problems with error variance and prediction emerge, the advantages of studying real-life interactions outweigh the disadvantages (p. 259).

In the absence of a solid body of knowledge or even clearly-defined constructs in the area of current investigation it is apparent that a qualitative approach is the most appropriate research method. Empirical works reviewed in the following sections are recognized as providing valuable information about certain identified variables but must be examined cautiously in light of the potential for bias. That is, when instruments assessing specific variables are presented to a group prior to thorough descriptive exploration the results may reflect a skewed, 'unnatural' perspective.

Prior to examination of the patterns of response among various cancer patient groups, an overview of the clinical picture of ovarian cancer will be presented. This discussion will provide information regarding the medical context of ovarian cancer patients.

Ovarian Cancer: Demographics, Clinical Course, and Treatment

Ovarian cancer showed an increase in incidence of approximately 4% between the years 1952 and 1977. Current estimates suggest that one of every 70 females born will develop the disease in her lifetime (Smith, 1985, p. 3). It ranks as the fourth leading cause of cancer death among women followed by malignancies of the breast, lung, and colon and rectum (Cancer Statistics, 1986, p.11). The five year survival rate for ovarian cancer has remained stable for the past twenty-five years and is estimated at 37% for all stages of disease and 21% for patients with invasive malignancies. (Cancer Statistics, 1984, p. 22). Cause of death is usually attributed to repeated bowel obstructions with resultant malnutrition. Infection is also a factor in many cases (Barber, 1986, p. 149).

The etiology of ovarian cancer is unknown, thus making prevention impossible. Current screening techniques are inadequate in the detection of the disease and early diagnosis is made difficult by the lack of distinctive symptoms. Early manifestations of the disease include vague abdominal discomfort and a variety of mild

gastrointestinal disturbances which are not usually considered to be diagnostically significant. Diagnosis is usually only possible following the development of the more serious symptoms of abdominal swelling, an abdominal mass, or pain, which are indicative of advanced cancer. The fact that the majority of patients have advanced disease at the time of diagnosis is considered to be the major factor contributing to the poor therapeutic results in ovarian cancer (Barber, 1986, p. 152).

The treatment regime usually includes a primary surgery consisting of removal of the uterus and both ovaries (total abdominal hysterectomy and bilateral salpingo-oophorectomy) (Hubbard, 1978, p. 117; Thigpen, 1985, p. 9). A course of monthly chemotherapy treatments typically follows. A 'second look' operation is considered an essential follow-up to chemotherapy to assess disease status and plan further treatment. Data have indicated that the second surgery plays a valuable role in increasing patient survival and comfort (Barber, 1986, p. 186).

The objectives of the primary surgery are precise diagnosis and accurate staging of the disease. Stage I disease is defined as tumor growth limited to the ovaries. Stage II includes growth involving one or both ovaries with pelvic extension. Stage III disease is diagnosed by the detection of metastases outside the true pelvis, positive retroperitoneal nodes, or involvement of small bowel or omentum. Stage IV disease involves malignant growth in one

or both ovaries with distant metastases (Smith, 1985, p. 3). Accurate staging is imperative to the determination of appropriate post-surgical treatment.

Following surgery, patients generally receive a course of chemotherapy. Protocols combining multiple drugs with different mechanisms of action, metabolic targets, time of onset of action and recovery, and target areas of toxicity have been shown to be most successful (Krakoff, 1981, p. 138). Combinations including cisplatin have been found to be particularly beneficial in the treatment of ovarian cancer and represent the treatment of choice in most cases. Adriamycin and cyclophosphamide are the agents most typically combined with cisplatin (Barber, 1986, p. 171; Eustace, 1980, p. 373). Recent research by Omura et al. (1986) provides further support for the benefits of cisplatin in the treatment of ovarian cancer. Their study of 227 women with Stage III and Stage IV ovarian carcinoma found that patients whose protocol included cisplatin as well as adriamycin and cyclophosphamide responded better (complete response rate 51%) than those receiving adriamycin and cyclophosphamide only (response rate 26%). Response duration was also significantly improved. Toxicity was noted to be more severe but tolerable (p. 1729).

As chemotherapy programmes become more aggressive and hence, effective, difficulties associated with increased toxicity must be overcome. High dose cisplatin

administration causes severe nausea and vomiting in virtually 100% of patients leading to potential problems regarding compliance with treatment (Eustace, 1980, p. 373; Harris, 1978, p. 194; Laszlo, 1983, p. 2). Fortunately, major strides in counteracting the problem of nausea and vomiting have also taken place (Lazlo, 1982, p. 6).

Studies of the effectiveness of various antiemetic agents under a number of treatment conditions continue in order to determine the best method for controlling chemotherapy-related nausea and vomiting. Berry-Opersteny and Heusinkveld (1983) examined the effects of prophylactically-administered antiemetics and found a significant reduction in post-chemotherapy vomiting. Patients receiving adriamycin and/or cisplatin were targeted as most in need of routine administration of antiemetics (p. 121). The drug metoclopramide (Maxeran) has been demonstrated to be particularly effective in the management of cisplatin-induced nausea and vomiting (Laszlo, 1983, p. 5; Laszlo, Gralla, Einhorn, & Wampler, 1983, p. 79). Critical elements for maximal efficiency of metoclopramide have been found to be: appropriate dose (2 mg/kg), route (intravenous), and schedule (30 minutes before chemotherapy and 1.5, 3.5, 5.5, and 8.5 hours after beginning chemotherapy). Patients frequently experience side effects including sedation, diarrhea, and extrapyramidal reactions (usually anxiety and/or restlessness) but find these to be much more tolerable than

the nausea and vomiting (Gralla, 1983, p. 72).

Recent advances in surgical techniques, chemotherapy programmes, and toxicity control have resulted in a more optimistic picture for women with ovarian cancer. Despite these improvements and promising developments, however, this disease significantly alters both physical and psychosocial domains and requires that patients and their families cope with an immense number of stressors.

Impact of Illness and Treatment

In the following discussion the results of recent research investigating the impact of cancer and its treatment on patients' physical and psychological functioning are presented. In addition, studies considering behavioral factors such as self-care activities and background factors such as age and sex of patients are reviewed. Finally, investigations addressing issues related to the influence of support systems such as families and social networks, hospital personnel, and patient groups on patients response to illness and treatment are discussed.

This review reveals that although the number of studies examining psychosocial issues appears to be increasing, a unifying theoretical position remains elusive. It would appear that, in many cases, correlational and predictive studies have prematurely preceded thorough qualitative investigation. Descriptive studies are emphasized by many as the necessary first-step

to theory (Morse, 1985; Seigal, 1983, p. 101). The results of these quantitative efforts, therefore, may be limited by potential bias. They are, nontheless, related to the current research questions and are, thus, presented in the following discussion.

Physical Side Effects

Studies investigating chemotherapy effects have, in the past, tended to focus on physiologic symptomatology (Harris, 1978; Peterson & Popkin, 1980). Side effects of combination chemotherapy include severe nausea and vomiting as well as possible renal, cardiac, and hematologic toxicity (Barber, 1980, p. 9). Cisplatin has also been found to produce ototoxicity in 30-50% of those who receive it (Peterson & Popkin, 1980, p. 151) and has been associated with impaired cognitive functioning not caused by depression and/or anxiety (Silberfarb, Philibert, & Levine, 1980, p. 600).

Nausea and vomiting are noted to be the symptoms that cause the most distress to patients as well as presenting a common management concern to nurses (Kennedy, Packard, Grant, & Padilla, 1981). Patients on chemotherapy protocols including cisplatin are almost certain to experience this side effect within one to four hours of receiving the drug. The symptoms usually last 24 hours, but for some patients persist for several days to a week. In addition to the devastating effects of the post-treatment symptoms these patients are particularly

prone to the development of pre-treatment nausea and vomiting over the course of their chemotherapy series (Eustace, 1980, p. 373; Morrow, 1982, p. 588). That is, many patients become nauseated before they receive the toxic medication. Weddington et al. (1984) found empirical support for this observation in their survey of 50 oncology outpatients receiving chemotherapy. They found that of those who reported post-chemotherapy nausea and vomiting 50% reported pre-treatment nausea with or without vomiting. The symptoms were evoked by thoughts of chemotherapy, sights, and specific odors and tastes. Age, sex, race, educational level, disease, and type of chemotherapy did not appear to be factors affecting anticipatory symptoms (p. 73). It is widely recognized by health care personnel and chemotherapy patients themselves that the incidence and severity of nausea and vomiting involves a large psychogenic element (Frytak & Moertel, 1981, p. 393; Morrow, 1982, p. 587).

Several studies have addressed the relationship between physical symptomatology and psychosocial distress in an effort to determine whether psychosocial problems are a consequence of physical impairments and, thus, more significant in patients with greater physical limitations or whether psychopathology is independent of physiological status. Results at this point are equivocal. What is clear, however, is that the great majority of chemotherapy patients must cope with a large number of treatment side

effects and that psychological distress is common.

Dunn (1985) found that 86.7% of her sample of chemotherapy patients experienced fatigue as a result of chemotherapy, 71% reported nausea, 62.2% reported appearance change and appetite changes. Of these, fatigue was reported to be the most intense symptom. She found a strong relationship between the presence of physical symptoms and the occurence of emotional distress and behavioral dysfunction.

In contrast, Meyerowitz et al. (1979) found that although all 50 breast cancer patients they interviewed reported adverse life changes as a result of chemotherapy, their level of distress was not related to the number or severity of physical side effects (p. 1616). The researchers concluded that, in addition to side effects, there were other factors that influenced patients' well-being. Also, despite the distress associated with the treatment protocol, 60% of the sample were pleased to have received the treatment and 74% stated that they would recommend the treatment to a good friend in a similar situation (p. 1617).

The ability of most patients to tolerate the negative effects of treatment was also noted by McArdle et al. (1981). They found that although 85% of breast cancer patients receiving chemotherapy experienced some degree of toxic side effects, most completed the full course of treatment and were able to resume normal activities

including employment. Nausea and vomiting were reported to be the most distressing side effects resulting in 4% of patients discontinuing treatment within the first three months. Significant psychiatric morbidity, particularly anxiety and depression, was also noted in their sample (p. 263).

It would seem, then, that although the occurence of physical problems as a result of cancer and its treatment is virtually universal there are other 'human' factors that intervene to alter the impact of the symptoms. In the present study exploring the experience of chemotherapy among ovarian cancer patients on cisplatin it would be expected that physical side effects would be severe due to the high toxicity of the treatment. Consideration of psychological factors that may influence patients' responses is, thus, important. Studies that have addressed psychological variables are discussed next.

Psychological Factors

Increased research efforts have recently been directed toward the investigation of psychological correlates associated with chemotherapy side effects. Most of these studies examine the role of anxiety and depression, although the influence of cognitive factors has also been explored.

In terms of general 'mental status' Dunn (1985) measured psychological symptomatology among 45 women on chemotherapy for treatment of breast cancer. She found

that 62% experienced depression, 60% experienced anxiety, 53% experienced hostility, and 50% experienced interpersonal sensitivity. Of these symptoms depression and anxiety were reported to be the most intense. Notably, however, most of the women reported only mild distress. As noted above, Dunn identified a strong positive correlation between emotional distress and physical symptoms.

In contrast to the high incidence reported above, Farber, Weinerman, and Kuypers (1985) found psychological symptomatology to be less prevalent. Thirty-four per cent of the 141 outpatients they assessed reported clinically meaningful levels of psychological distress. Less than 20% of the patients reported high levels of depressive symptoms and about 13% reported high levels of anxiety. An additional 14% of the patients reported intermediate levels of these symptoms (pp. 114-116). Variability in measures as well as in characteristics of the target groups could account for the different levels of measured distress between this and Dunn's study (cited above). Also notable was the fact that this sample demonstrated no relationship between psychological distress and disease or treatment status.

In addition to these investigations assessing psychological distress, several studies have isolated the variables of anxiety and depression to examine their specific relationship to a number of variables.

Anxiety

Anxiety has been strongly implicated as a major factor contributing to the development of anticipatory nausea and vomiting in chemotherapy patients. Altmeier, Ross, and Moore (1982) found that patients who manifested prechemotherapy vomiting were significantly more anxious and depressed than those who were not anticipatory vomiters (p. 203). Similar findings were reported by van Komen and Redd (1985). In addition, these researchers determined that those with anticipatory symptoms were more likely to have experienced posttreatment nausea and vomiting. Thirty-three per cent of the 100 patients tested reported having experienced anticipatory nausea and 11% reported anticipatory vomiting.

It would appear that anxiety pervades many aspects of the treatment experience. In a recount of her personal experience of receiving chemotherapy Buckalew (1982) described a monthly "cycle of anxiety". Tension mounted 2 weeks prior to admission, reaching a peak during treatment, and decreasing after discharge. Various hospital odours increased her anxiety as did discussing her history and treatments with new roommates. Buckalew also described lack of confidence in the knowledge and expertise of nursing staff, fear of intravenous insertion, knowledge of the inevitable, unpleasant after-effects of the treatment, and isolation as factors contributing to her anxiety.

A similar cyclic pattern of anxiety was noted among

patients receiving radiation implants (Anderson, Karlsson, Anderson, & Tewfik, 1984). Levels of anxiety increased as the time for treatment approached and did not decrease on receiving a subsequent treatment. This finding could have implications for ovarian cancer patients receiving a second look surgery who may be expected to be less anxious about the second surgery because of their previous experience. Another interesting outcome in this study was that patients with lower levels of pretreatment anxiety were found to experience greater disruption after their treatment. That is, those who were less anxious prior to receiving the radiation implant showed increased anxiety and more disruption in their activity levels after treatment as well as greater discomfort during treatment. Results such as these point to the complex nature of anxiety. Its function in influencing patients response to illness and treatment remains unclear.

Depression

Assessment of depression among cancer chemotherapy patients is fraught with measurement difficulties. Somatic symptoms such as fatigue, sleep disturbance, and altered appetite patterns that are typically included in instruments assessing depression are also concomitants of cancer and its treatment. As a result of this confounding factor, findings of many studies may represent overestimates of depression. One such study was that conducted by Bukberg, Penman, and Holland (1984). In this

study DSM-III diagnostic criteria were applied to patient self-report and interview report rating scales to determine the prevalence of depression in a group of 62 oncology inpatients. They found that 42% met the criteria for nonbipolar major depression while 24% were seen as 'severely' depressed and 18% showed moderately severe symptoms. Examination of medical and demographic variables showed that only greater degree of physical disability was clearly associated with depression. Among those patients who were less disabled, poor social supports and frequent negative life events were associated with depression (p.210). Evans et al. (1986) also used DSM-III criteria to assess 83 inpatients with gynecological cancer. They found that 23% had major depression. The dexamethasone suppression test (DST) and the thyrotropin-releasing hormone (TRH) were not found to be sensitive or specific enough to be useful in distinguishing depression (p. 451).

The relationship between psychological and physical symptomatology was assessed and interpreted in a markedly different manner by Layne, Heitkemper, Roehrig, and Speer (1985). Applying a motivational theory of depression they hypothesized that cancer patients would be depressed, would exhibit low motivation for rewards, and that they would be less optimistic than control subjects. All of their hypotheses were supported. Based on their findings it was suggested that the diagnosis of cancer precipitates depression because patients' adaptive illusions and

optimistic expectations are shattered. They supported this with the observation that levels of physical discomfort did not vary between groups. It was further speculated that some of the symptoms that accompany cancer such as low appetite, sleep disturbances, anhedonia, and low motivation might be psychological rather than physical. That is, they proposed that these symptoms are aggravated, if not caused by an adjustment reaction with depressed mood (p. 143).

An interesting study by Goldberg, Wool, Glickman, and Tull (1984) attempted to look at physical and social factors associated with depression in lung cancer patients and their spouses. They found that the level of depression in both patients and spouses decreased in the four to six months following diagnosis. During the first few months patients' depression was not related to physical status and was similarly unrelated to their level of social interest and involvement. After six months, however, patients' depression was found to be related to their physical status. It would appear that, over time, patients became depressed about their physical limitations. In contrast to this, the spouses depression was associated with social interest and involvement and not with the patients' physical status (p. 79).

Cognitions

Few studies have directly explored the relationship of cognitions and patients' response to illness and treatment. Altmeier et al. (1982) compared patients who exhibited

prechemotherapy nausea and vomiting to those who did not manifest this symptom. They found that the cognitions of pretreatment vomiters were inhibitive to coping whereas nonvomiters had thoughts that were facilitative of coping. Inhibitive cognitions included thoughts related to giving up or statements such as 'there's no relief in sight'. Along with these negative cognitions she noted greater anxiety and depression among vomiters (p. 202). Zook and Yasko (1982) made a similar conclusion when they found that patients who entered into treatment having had a negative past experience with someone on chemotherapy on which they might dwell were most likely to experience nausea and vomiting (p. 80).

An area more peripherally related to cognitions is that of body image. Andersen and Jochimsen (1985) found that 82% of the gynecologic cancer patients they assessed reported poor body image evaluations. This was in contrast to 31% of the breast cancer patients and 38% of the women in the healthy samples. Both breast and gynecological cancer patients reported significantly lower levels of sexual behavior than the healthy patients (p. 28). Although the researchers did not speculate on the psychosocial implications of these negative self-perceptions it would seem likely that negative cognitions related to body image would be associated with increased levels of distress. Further investigations are required in this area.

Research strongly supports the notion that a number of psychological factors are associated with cancer and its treatment. Levels of anxiety and depression appear to be particularly high among cancer patients. It is not clear at this time, however, just how the experience of cancer influences the development of psychopathology nor is it understood how patients' psychological resources influence their experience of cancer. Further exploration of the patient's perspective such as that undertaken by the present study may be illuminative in this regard. In addition, it is important to examine other potentially influencing factors such as patients' behavioral patterns.

Behavioral Factors

Dodd (1982; 1983) emphasized the importance of considering behavioral as well as cognitive and psychoemotional factors associated with cancer treatment. She examined chemotherapy side effects and looked at the self-care behaviours adopted by patients to alleviate them. Although an average of more than seven chemotherapy-related side effects was reported, self care techniques to manage side effects were notably lacking. Many people were reluctant to complain about the treatment as it was expected to "cure" their disease. They believed that the side effects were a consequence that simply had to be endured and, as a result, took no actions to alleviate their symptoms (p. 451). This discrepancy between experienced side effects and initiated self-care behavior

was attributed to lack of informaton from physicians and nurses and concomitantly the patients' limited knowledge of self-care measures. A follow-up study (1983) indicated that patients who had been given information on side-effect management techniques initiated more self-care behaviors with a higher degree of perceived effectiveness. Lack of objective information regarding their illness and treatment was also speculated by Bean, Cooper, Alpert, and Kipnis (1980) as inhibiting patients' ability to assume care for themselves (p. 259).

The area of self care was also examined by Fernsler (1986). She conducted a descriptive study comparing the perceptions of patients and nurses regarding self-care deficits associated with cancer chemotherapy in an outpatient setting. Nearly 30% of the reported deficits were related to the category of activity and rest suggesting a need for nurses to assist patients in this area. Patients reported more self-care deficits than did nurses, which indicates that nurses might not have been aware of the extent to which services were required by patients. Also, patients were generally more concerned than nurses about the physical side effects of their treatment and less concerned than the staff about psychosocial problems. Overall, nurses did not accurately perceive the extent to which patients required assistance (p. 57).

In a study considering behavioral factors in a less

direct manner Parsons (1977) explored patients' perception of their illness, their needs (physical, emotional, social, spiritual, environmental, financial), and the agents they identified which helped them meet these needs. Her subjects included twenty cancer patients at various stages of illness and treatment. She found that patients presented their physical complaints in a calm and matter-of-fact manner and were similarly controlled in their discussion of emotional and social problems. It was speculated that because considerable time had passed since the initial diagnosis, these patients had thought about and sorted out their feelings related to their illness. She also found that, despite her focus on deficits and needs, the patients demonstrated incredible strengths and coping abilities (p. 23).

Examination of behavioral patterns exhibited by patients in response to their illness or treatment-related symptoms offers further information regarding their personal modes of coping with stress.

Background Factors

In addition to psychosocial and behavioral elements, background factors such as the age of patients and the extent of their disease contribute significantly to patients' response to illness and treatment.

A number of studies have considered the role of age in influencing cancer patients' adjustment. Most studies concur that adjustment to the diagnosis and treatment of

cancer is more difficult for younger patients. Ganz, Schag, and Heinrich (1985) found that younger patients experienced greater psychosocial disruption from cancer, especially in relation to work and chemotherapy, than did elderly individuals (p. 429). Similarly Fobair and Mages (cited in Novotny, Hyland, Coyne, Travis, & Pruyser, 1984, p. 37) noted greater psychological symptoms among younger patients and a calmer, more philosophical attitude toward illness among the elderly. They also found, however, that the younger patients showed a greater capacity to develop new interests in their lives and were less inclined to be concerned with physical changes and limitations. Jamison (cited in Novotny et al., 1984, p. 38) also found that older women adjusted more easily to mastectomy than did younger women.

Taylor et al. (1985) attempted to identify the relationship between illness and treatment-related factors and overall adjustment to breast cancer. Their study of 78 women concluded that prognosis and type of surgery had significant effects on psychological adjustment, but that other factors such as the degree of disability and type of treatment (radiation, chemotherapy, or no treatment) did not.

A variety of medical status variables such as extent of disease, prognosis, and treatment have been examined to determine their impact on adjustment. Unfortunately, however, different forms of assessment and different means

of interpreting data have been utilized resulting in discrepant and, at times, confusing findings. For example, Weisman (1977) found that medical data (staging of the illness, prognosis, etc.) obtained during initial hospitalization accounted for 40 to 60 percent of the variance of patient distress reported six months later. Similarly, Cassileth and associates (1985) found that the extent of the disease was the major factor determining prognosis, overriding the potentially mitigating influence of psychosocial factors. They measured survival and relapse time of patients with unresectable cancers and those with Stage I and Stage II melanoma or Stage II breast cancer.

In contrast to these findings, however, are those of Gordon (cited in Freidenbergs et al., 1981-82, p. 313) who found that medical data accounted for only 12% of the variance of patient report of problems 6 months post-hospital discharge. Similarly Schonfield (cited in Freidenbergs et al., 1981-82, p. 313) and Morris, Greer, and White (1977) found anxiety and depression to be more potent predictors of future psychosocial difficulties than medical data. Meyerowitz et al. (1979) also found the level of psychosocial distress to be unrelated to the number or severity of physical symptoms.

In light of these equivocal findings it seems imperative that the factors of age and extent of disease be explored in a descriptive manner to provide a preliminary

basis for generation and testing of hypotheses. The present study, by means of open-ended, patient-directed interviews aims to accomplish this.

Support Factors

The effects of cancer and its treatment are influenced by the nature and availability of psychosocial support in the patient's environment. This was highlighted by the results of Todres and Wojtiuk's (1979) study that examined the side effects of chemotherapy and its impact on the lifestyle of breast cancer patients. They found that patients attributed problems in the areas of family relationships, sex life, and employment to chemotherapy's negative side effects (p. 285). Other researchers are giving increasing recognition to the important role of patients' relationships with family, friends, and health care personnel. Issues related to family support, friendship and co-patient networks, and the function of health care personnel as support providers are being considered from a variety of perspectives.

Family and Social Networks

Patients generally identify immediate family members as their most important source of support. Examination of support networks among 357 recently diagnosed breast, endometrial, and ovarian cancer patients showed that married patients perceived their spouse to be the most important source of social support (87.7%). Friends were ranked as second most important (81.4%), relatives (78.6%),

and children (73%). It was notable that widows were most likely to seek support from their children (92.8%) and to perceive friends as a less reliable source of support than were separated women. Also of interest was that in this sample patients generally felt that the support they received was adequate. Only 17.2% said they felt isolated or alone since being diagnosed with cancer. The most important type of support appreciated by the patients was emotional, having someone to talk to and listen to them. Other important beneficial types of support were instrumental in nature and included such things as housework and meal preparation (Smith, Redman, Burns, & Sagert, 1985).

Cross-cultural studies show that families are considered by patients to be their major source of support. A sample of cancer patients in Egypt perceived their support network to be stable and of high quality, citing spouse and relatives as providing the great majority of support (Lindsey, Ahmed, and Dodd, 1985). Similarly, Kesselring, Lindsey, Dodd, and Lovejoy (1986) found that Swiss patients identified family as the most important source of support. These patients reported having fewer people in their network, however. These results were contrasted with those of a sample of employed adult Americans who identified fewer people in their network with the largest proportion of support coming from the 'friends' category. Notably, in both Egyptian and American samples

health care providers were perceived as contributing minimal support.

A few studies have directed attention to exploration of the dynamics within families who are coping with cancer. For example, in a qualitative study of the family cancer experience Thorne (1985) found that the families attributed the maintenance of normalcy and dignity as the essential ingredients to successful coping. Specific strategies utilized varied from family to family but within each family the strategies fit with their philosophy or family 'life concept'.

Perceptions regarding the demands imposed on families by breast cancer were examined by Lewis, Ellison, and Woods (1985). They found that partners reported fewer illness demands than did their wives. Being able to attribute demands to the illness appeared to be facilitative of positive coping in families. Analysis of open-ended interview data revealed the major areas of demand to be those related to treatment effects such as hair loss, weakness, and anorexia. Changes in self-image, changes in relationship with the social network, unpredictability and uncertainty, responses of health professionals, and vulnerability to illness recurrence were also among the demands reported. Husbands were most likely to cite financial demands and concerns related to feeling unable to adequately assist their wives during difficult times whereas wives reported change in self-image as most

distressing.

In a further effort to understand family dynamics, Tringali (1986) studied family members of 25 patients at various phases of illness to determine their perceived cognitive, emotional, and physical needs. In all phases of illness family members ranked cognitive (informational) needs as most important to them. These included such things as use of understandable terms and honest answers about the patient's disease, treatment, and prognosis. Emotional needs such as the need for hope and to trust the care provider's expertise and concern for the patient as a person were also identified though ranking lower than informational. Physical needs ranked low in degree of importance.

The present study will ascertain the degree to which family and social support is considered important to the selected ovarian cancer patients. The nature of support provided by families and the impact of illness and treatment on family and social relationships will also be examined.

Hospital Personnel

There has been very little systematic investigation of the role of hospital personnel in providing support to cancer patients. Clinical observations combined with the few studies that have addressed the issue suggest that it is an important consideration, however. Although Lindsey et al. (1985) found that patients did not perceive health

care personnel to be supportive, Molleman et al. (1984) noted that patients depended on experts as their main resource in relieving uncertainty related to their illness and treatment.

Blanchard, Ruckdeschel, Fletcher, and Blanchard (1986) examined factors in the physician-patient relationship that influence patient satisfaction. Overall, patients reported a high level of satisfaction with their oncologist. Older patients tended to report greater satisfaction as did people with a poorer medical prognosis. Physician behaviors that tended to contribute positively to patient satisfaction were use of their first names and attempts to establish privacy during an exam. Patient satisfaction was noted to decrease when the information conveyed by the doctor was negative. The physician-patient relationship was also negatively influenced when the oncologist initiated discussion of the role of family and when he/she examined nontruncal areas.

As technological advances continue to change the nature of patients' experience within the health care system it becomes increasingly necessary to direct research toward gaining a more clear understanding of the influence of professionals in the field on patients' psychological as well as physical well-being. Among the ovarian cancer patients selected for the current investigation, for example, interactions with health care providers including dieticians, pharmacists, nurses, and doctors are frequent

and may significantly influence patients' perceptions of and responses to their situation.

Patient groups

The need to provide patients with psychosocial support as well as information about cancer and its treatment has been recognized and, as a result, a number of educational and therapy programs have been initiated. Documented evaluations of some of these programs attest to their overall benefit to patient well-being but it would appear they are limited in their ability to influence change in patients' behavior patterns.

Studies by both Miller and Nygren (1978) and Heinrich and Shag (1985) indicated that participation in a structured educational program did not result in increased activity levels in patients nor did it cause them to alter their previous patterns of coping. Patients in both studies did describe the sessions as a positive experience, however, and appreciated the group support that arose out of them. They generally reported a greater appreciation for life and a more positive attitude toward living as a result of their participation in the program.

Goldberg and Wool (1985) conducted a study to determine the effects of a counselling intervention on psychosocial adjustment among cancer patients and their spouses. They found no differential change over time between the study group and the control group in measures of emotional, social, or physical functioning. Patients

and their spouses in both groups showed a positive adjustment to the illness over time. The researchers speculated that their findings point to the need to develop screening measures to identify those in need of intervention.

In contrast to these negative findings, Cain, Kohorn, Quinlan, Latimer, and Schwartz (1986) reported positive results from their short-term counselling model which included high informational and problem-solving components. Gynecological patients who had been part of either a group or individualized counselling showed reduced psychosocial distress following the program and maintained the benefits to follow-up one year later.

A less structured approach was advocated by Berger (1985). She described the benefits of her drop-in family support group designed to provide on-going support for cancer patients and their families. The flexibile nature of the program was felt to be a major advantage.

The benefits of patient support groups as well as educational and therapy groups need to be further evaluated. It is unclear at this time whether patients consider that there is a need in this regard. The current study may shed some light on this issue.

Coping Theory

Current literature supports the premise that the type, amount, or frequency of stress does not effectively explain the observed and reported variability in psychological,

physical, and social outcomes. Rather, it is suggested that how people react to, or "cope with", stress is a critical factor affecting adjustment and well-being (Coelho, Hamburg, & Adams, 1974, p. 27; Roskies & Lazarus, 1980, p. 38). That is, the stimulus-response model has been repeatedly shown to be inadequate in its ability to predict outcomes. It ignores the importance of individual differences and fails to consider that life events may have different effects on different people and that individuals possess variable resources for coping with stress (Roskies & Lazarus, 1980, p. 38; Holroyd & Lazarus, 1982, p. 21).

Unfortunately, despite increased recognition of the importance of coping and an abundance of research in the area, no unifying theoretical position exists (Singer, 1984, p. 2310). Some of the difficulty in this regard has been attributed to the the lack of clarity in the definition of the construct. For example, in many cases the terms 'adjustment' or 'management' are used interchangeably with coping making it difficult to clearly delineate the boundaries of investigation.

Several theoretical models describing the process of coping have been postulated. Among the most well-known and relevant to the current discussion are those of Lazarus and his colleagues (1980); Roth and Cohen (1986); Pearlin and Schooler (1978); and Taylor (1984). Though each presents a unique perspective and distinctive terminology they are clearly overlapping and often complementary in their

conceptualizations. As stated in Chapter I, the present study adopts the definition and description of coping put forth by Lazarus and his associates.

Lazarus has formulated a dynamic transactional model of coping that moves away from the traditional cause-effect relationships in stress theory. In this paradigm the person and the environment are seen in an ongoing reciprocal relationship, each affecting and in turn being affected by the other (Folkman & Lazarus, 1980, p. 223). Coping becomes an active force in shaping both what is happening and what will happen in a given stress episode.

Lazarus defines coping as "the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflicts among them" (Folkman & Lazarus, 1980, p. 223). The functions of these efforts are twofold: the management or alteration of the person-environment relationship that is the source of stress (problem-focused coping) and the regulation of stressful emotions (emotion-focused coping)(Folkman & Lazarus, 1980, p. 223). Ways of coping include direct action, action inhibition, information search, and intrapsychic modes (Roskies & Lazarus, 1980, p. 46).

Roth and Cohen (1986) also present a bipartite model that describes approach and avoidance as the basic modes of coping with stress. They define coping as the cognitive and emotional activity that is oriented either toward (approach) or away from (avoidance) threat (p. 813).

Avoidant strategies are useful in reducing stress and preventing anxiety from increasing. Approach strategies allow for appropriate action to be taken and for affect to be ventilated. It is suggested that use of one or the other modes would be more or less beneficial depending on the nature of the stressful situation. For example, avoidance is thought to be better for coping with situations perceived to be uncontrollable (p. 818).

Pearlin and Schooler (1978) postulate that there are three major types of coping, each with unique functions: 1) responses that change the situation out of which strainful experience arises; 2) responses that control the meaning of the strainful experience after it occurs but before the emergence of stress; and 3) responses that function more for the control of stress itself after it has emerged. The first category includes those responses that are direct actions such as negotiation or seeking information. The second includes such things as making positive comparisons or selectively ignoring noxious aspects of the situation. The third type of coping responses includes activities such as trying not to worry, relaxing, or accepting hardship because it was meant to be (p. 7).

Taylor (1983) has proposed a theory of cognitive adaptation to explain how people cope with threatening events. She postulates that the readjustment process focuses around three themes: a search for meaning in the experience, an attempt to regain mastery over the event in—

particular and over one's life more generally, and an effort to enhance one's self esteem - to feel good about oneself again despite the personal setback (p. 1161). Her analysis of interviews with 78 women with breast cancer showed that, indeed, there was an attempt to find meaning in, or a reason for, the development of cancer. Ninety-five per cent of the women offered some type of causal explanation for why their cancer occurred. Two thirds of them believed that they had some control over the course or recurrence of their disease and a substantial number adopted either psychological techniques or direct action to gain control of their situation. With regard to the third theme these women tended to bolster their self-esteem by comparing themselves with someone who they perceived to be worse off (p. 1166). Taylor maintains that these cognitive 'illusions' serve as buffers against present as well as potential threats (p. 1161).

Several investigators have explored the role of buffers or mediators in the management or alleviation of stress. Lazarus emphasized the importance of cognitive appraisal as a mediator between stress and coping. Appraisal provides meaning to the situation and coping efforts are, thus, influenced by whether one appraises the situation as harmful, threatening, or challenging (1982, p. 176). Other researchers have looked at the influence of certain psychological or physical characteristics in mediating the impact of stress. Krause and Stryker (1984)

examined the role of locus of control in this regard. They found that men who believed that events in their lives were under their own control (internal locus of control) experienced less psychophysiological distress than those who believed that events were determined by outside forces such as luck, fate, or chance (external orientation). Having moderate internal locus of control beliefs appeared to offer the greatest buffering role, resulting in an increased likelihood of initiating actions to counteract the effects of stressful situations (p. 787).

Using a somewhat similar design, Scheier and Carver (1985) examined the buffering role of optimism and its relationship to coping among a sample of undergraduate university students. They found that optimistic subjects reported being less bothered by physical symptoms during the stressful assessment time than did less optimistic students. In addition, optimism was positively correlated with active coping and with the seeking of social support.

The roles of personality style and constitutional predisposition as mediators in the coping process were investigated by Kobasa et al. (1981) in a prospective five year study. Integrating various theoretical perspectives they formulated a description of 'the hardy personality style' as marked by characteristic coping patterns. These patterns were identified by the presence of commitment, control, and challenge. Instruments selected to measure the hardiness classification were used to determine the

relationship of hardiness to the development of illness. Constitutional predisposition to illness was determined by the presence of illness among the subjects' parents. Results indicated that personality-based hardiness served as a resistance resource against illness whereas constitutional predisposition, and stressful life events increased the risk of subsequent illness (p. 377).

The efficacy of coping is often evaluated in terms of how well it prevents hardships from resulting in emotional stress (Pearlin & Schooler, 1978, p. 8) or physiological symptomatology (Kobasa et al., 1981). Lazarus and his colleagues depart from this focus on 'mastery' and 'good copers vs bad copers' presenting, instead, a description of coping in terms of efforts toward 'management'. Their research results indicate that people are more variable than consistent in their patterns of coping and that the type of coping strategies utilized are influenced by the context and appraisal of the stressful situation. They found that people used both problem-focused and emotion-focused coping in virtually every stressful situation and tended to emphasize problem-focused coping in stressful work contexts and emotion-focused coping in health contexts. Appraisal of the changeability of the situation also influenced coping. Those situations appraised as being changeable resulted in greater problem-focused coping and those perceived to be unchangeable resulted in more emotion-focused coping

(Folkman & Lazarus, 1980, p. 230).

In summary, it is clear that coping plays an active role in an individual's attempts to manage or master stressful situations. Although theoretical perspectives vary in their specific definitions and conceptualizations of the coping process, there is considerable consensus among the theorists. It appears that coping involves both behavioral and intrapsychic components and that the coping strategies employed depend on the context of the stressful event as well as the individual's appraisal of the situation.

Examination and understanding of coping patterns among a particular group such as ovarian cancer patients is enhanced by an awareness of the general theoretical positions in the area. Information relating to 'non-clinical' populations also provides a valuable framework within which to analyze data pertaining to a selected target group. Specific studies relating to cancer patients are presented in the following discussion.

Coping Strategies in Cancer Patients

A number of studies have assessed the coping strategies utilized by cancer patients. Bloom (cited in Novotny et al., 1984) noted that although it is difficult to find a common response pattern to the experience of having cancer, coping tends to be either behavioral or intrapsychic. This conceptualization is clearly in line with that presented by Lazarus et al. (1980) who categorize

coping functions as either problem-focused or emotion-focused.

Studies identifying specific coping strategies among cancer patients generally support this categorization. For example, Friedman's (1980) outline of the ten major coping strategies used by cancer patients reflects both behavioral (problem-focused) and intrapsychic (emotion-focused) components. The list of strategies she identified through a review of the literature includes: seeking information, seeking support, following medical orders, returning to work, coping as in past, tension reduction, denying and escaping, finding meaning for disease, preparing for death, and blaming.

The strategy of information-seeking was also found to be commonly used among the groups studied by Felton and Revenson (1984). They compared coping patterns of patients with diseases perceived as somewhat controllable such as diabetes to patients with diseases perceived as uncontrollable such as cancer. Results from both groups indicated that the strategy of information-seeking had emotional benefits for patients and resulted in decreased negative affect whereas the strategy of wish-fulfilling fantasy was associated with poor adjustment.

Another study comparing coping patterns of different patient groups assessed 42 patients with early stage cancer and 31 patients with advanced stage cancer along with their mates (Gotay, 1984). Taking firm action was the most

frequently-mentioned coping strategy. The early stage patients also tended to frequently employ information-seeking whereas the advanced stage respondents were more inclined to rely on religious faith. Both groups used the strategy of talking to oneself. Overall, the similarities among reactions of early and advanced stage patients and their mates were more striking than were the differences.

Molleman et al. (1984) also found the strategy of self-instruction to be widely used by patients to help them cope with uncertainty and anxiety. Seeking contact with experts was shown by their sample to be the most effective means by which to reduce uncertainty (p. 478).

Taylor, Lichtman, and Wood (1984) found that the chemotherapy patients they interviewed utilized a variety of coping strategies to deal with the side effects of treatment. Thirty-five per cent used psychological techniques such as positive thinking, self-hypnosis, and relaxation; 22% used medications such as tranquilizers and anti-nausea agents; and 16% used sleeping to help them cope with negative side effects. Among this group 72% said that the coping strategies they used were effective. It is notable that although over half of the patients described the side effects as 'very unpleasant' the rate of compliance to the treatment regime was very high (92%).

A number of researchers have attempted to identify the behaviors or attributes of patients demonstrating 'good

coping' or 'positive adjustment'. Sanders and Kardinal (1977) interviewed asymptomatic leukemic patients being treated with monthly maintenance chemotherapy. The authors defined adaptive coping behaviors as those that served the purpose of adjustment to illness and disability. Adaptive coping mechanisms were identified in those patients who coped with their situation by denying they were sick, who joined with fellow patients to form a "hospital family", and who participated in grieving another patient's death as a form of anticipatory grief of their own losses (p. 952).

Timko & Janoff-Bulman (1985) found a relationship between patients sense of invulnerability to a recurrence of cancer and positive psychological adjustment. That is, women who reported feeling relatively invulnerable to cancer in the future coped more effectively. Their beliefs about perceived invulnerability, as predicted by perceived success of mastectomy and perceived future avoidability of cancer, could not be accounted for by differences among them in terms of the seriousness of their illness. Their perceptions regarding the threat of cancer did not appear to correspond to the actual threat posed by the disease.

In a sample of 300 women with cancer studied by Cobliner (1977) it was found that those who demonstrated successful adjustment were more likely to possess a high self-image, have high faith in doctors and in the efficiency of the treatment, have a desire and opportunity to confide their worries to another, and be involved in a

satisfying occupation or activity as well as in a good relationship with a significant other. Congruence between life expectations and the degree of their attainment as well as successful attempts with crisis resolutions in the past were also shown to be associated with what the researchers identified as successful adjustment.

From his studies of coping strategies among cancer patients Weisman (1977, 1979) identified good copers as those who face facts, find something favorable in their situation, then confidently comply with the doctor's recommendations. Poor copers were observed to use suppression, passivity, stoic submission, and a variety of tension reducing measures.

Another means of identifying good coping is to look at the relationship between coping strategies and survival. In one such study Derogatis et al. (1979) correlated length of survival with psychological status among metastatic breast cancer patients with similar clinical status. It was found that long-term survivors were more anxious, depressed, and alienated. They seemed better able to externalize their negative feelings than short-term survivors who revealed significantly lower levels of hostility and higher levels of positive mood. Patients who died more rapidly appeared distinctly less able to communicate dysphoric feelings, particularly those of anger and hostility.

It would appear then, that patients utilize a variety

of strategies to manage the stress imposed on them by their illness and treatment. Evaluation of the effectiveness of these strategies is difficult, however, as the criteria by which their effectiveness is measured are often arbitrary, unclearly defined, and imposed on the situation externally. For example, it is not clear that currently utilized measures of effective coping are actually measuring that variable in a consistent or appropriate way. That is, what patients perceive to be effective coping may not necessarily coincide with what clinicians or researchers have operationally defined as effective coping. Indeed, the findings of Fernsler (1986) that show patients and nurses varying considerably in their perceptions of self-care deficits points to the need to gain further understanding of the patients' perspective before making assumptions about their needs.

Conclusion

The current literature in the areas of coping and psychosocial oncology provides encouraging evidence of increased attention to psychosocial as well as physical factors in understanding cancer patients' response to illness and treatment. Clinical insights and concerns have stimulated research efforts directed toward consideration of the relationship between a number of physiological, psychological, and behavioral variables. Unequivocally, cancer and its treatment result in physical distress to patients. Response to those physical symptoms varies

widely, however. Examination of psychological factors indicates that people with cancer tend to display more psychological symptomatology than their non-clinical counterparts. Anxiety and depression appear to be particularly prevalent. The nature of people's cognitions has also been found to play a role in influencing how they respond. In terms of background factors, research suggests that older patients adapt more easily to the diagnosis of cancer. Patients rely on support from family members and friends as they deal with the stress of their illness. Support from professionals and co-patients appears to be less influential, though still important to the enhancement of overall well-being.

Finally, coping patterns tend to fall within Lazarus' (1980) conceptualization of serving 'problem-focused' or 'emotion-focused' functions. Specific strategies vary widely between patients and evaluation of coping effectiveness is hampered by lack of a clear definition of 'good coping'.

The present study adds to currently available information with an indepth and comprehensive exploration of the patient's experience of chemotherapy. It emphasizes the importance of examining the impact of illness and treatment from the patients' perspective. Given the lack of a unifying theoretical perspective in the area, further qualitative investigation is clearly essential to provide a sound basis for future research and clinical interventions.

Chapter III

RESEARCH DESIGN

The purpose of the present study was to gain an understanding of ovarian cancer patients' experience of illness and chemotherapy treatment. The design was qualitative in nature, focusing on obtaining the patient's perspective of her situation. In accordance with the goals of qualitative research, the design was flexible, allowing for ongoing evolution as the study proceeded (Bogdan & Biklen, 1982, p. 55).

Chapter III outlines the design and methodology of the current investigation. The manner in which the sample was selected is described, procedures followed in the study are discussed, the process of data analysis is outlined, and measures for dealing with ethical issues that could have arisen are presented.

Sample

Participants were selected from those ovarian cancer patients receiving chemotherapy through the Day Care Unit of the Cross Cancer Institute. The sample included four patients determined by consensus of the ovarian cancer research nurse, unit head nurse, and investigator to be "very different from each other". The group included patients who were at different points in their course of treatment and who had demonstrated varying responses to treatment. In addition, variability in age and other demographic characteristics was sought. These criteria were

imposed in an attempt to increase the heterogeneity of perspectives. The procedure of selecting subjects based on certain characteristics they possess is distinctive of qualitative research and is clearly divergent from sampling procedures in a quantitative design where attempts are made to randomly select subjects and to control for extraneous variables (Bogdan & Biklen, 1982, p. 38). It must also be noted that the sample size is necessarily small in this type of design, allowing for indepth examination of each subject.

Participants were required to be able to speak and understand English.

Procedure

The treatment protocol for patients participating in the study included monthly intravenous administration of cis-platinum and cyclophosphamide. Antiemetic medication was also routinely given. Patients typically arrived at the Day Care Unit at approximately 8:00 A.M. on the day of their treatment and remained for about 6 hours. Candidates for the study were introduced to the researcher by either the head nurse or the ovarian cancer research nurse and informed about the study. Procedures of the study were reviewed, questions answered, and a consent form signed (Appendix A). Patients who agreed to participate were observed throughout the day and interviewed at an appropriate time while receiving their treatment. An appointment for the home visit was set for an available

time during the following week.

Methods of data collection included observation and semi-structured interviews. Data were gathered by interviewing patients and observing their interactions during treatment sessions in the hospital as well as in their home environment. Field notes were taken to record observations in both settings. The initial interview consisted of demographic data gathering as well as discussion with patients regarding chemotherapy. Their experiences of the current treatment program and their perceptions of how they cope with their illness and treatment were explored.

Data collection occurred in the context of the following research questions: 1) How do ovarian cancer patients experience their treatment? That is, what does it feel like, physically and emotionally, to be receiving aggressive anti-cancer drugs? 2) How do ovarian cancer patients receiving chemotherapy perceive their treatment? That is, what do they think about their treatment and how do they conceptualize it? 3) What coping strategies do ovarian cancer patients currently utilize to cope with their illness and treatment? What is their perception regarding the effectiveness of these strategies? The seven questions in Appendix B served as a more specific guideline for the interviews. These open-ended questions allowed the subject to play a dominant role in defining the content of the interviews and, subsequently, the direction of the

study (Bogdan & Biklen, 1982, p. 136).

Data collected from the initial interviews were analyzed to identify relationships and themes and to direct further investigation. That is, successive interviews and observations were built upon information gained from the previous ones. Observations of patients during their treatment sessions included "following them through" their complete routine on the Day Care Unit. The final home visit interview allowed the researcher a second opportunity to observe patients in their home environment and also enabled termination of the patient-researcher relationship to take place in a relaxed atmosphere.

Data collection took place over an eleven week period and included observation of two successive monthly treatment sessions and two home visits. The first home visit took place between the two treatment days. The final visit was scheduled for a date following the second observed treatment.

Data Analysis

Data analysis in qualitative research is a process of systematically organizing interview transcripts, field notes, and other material accumulated during data collection to enable presentation of the information to others (Bogdan & Bilken, 1982, p. 55). In this study the analysis focused on generating categories and discovering relationships between these categories. Consistent with suggested procedures for analyzing qualitative data, coding

categories were developed to sort information (Aamodt, 1982, p. 213). Transcripts were color coded according to the method described by Field and Morse (1985, p.78). The left margin of each page was marked with a distinguishing color for each informant and for each interview. Interview data were studied to ascertain the essence or meaning and categorized accordingly. For example, one category that arose was "physical response to treatment". Each time information of that nature arose in the interviews it was placed in an envelope marked "physical response to treatment". As more data were added, subcategories emerged. Throughout the analysis the investigator looked for overall, integrating "themes" within the data. Data analysis proceeded concurrently with data collection.

Concerns regarding reliability and validity of qualitative data frequently arise (LeCompte & Goetz, 1982, p. 31). In qualitative research reliability is seen as the fit between what is recorded as data and what actually occurs in the setting under study, rather than the literal consistency across different observations (Bogdan & Biklen, 1982,p. 44). Thus, reliability is enhanced by the following:

1) careful description of the types of people selected as informants;

2) delineation of the decision-making process by which informants were chosen;

3) selection of informants who represent a broad range of

perspectives (Goetz & LeCompte, 1984, p.215). Chapter IV includes a detailed description of the participants as well as a discussion of the criteria and process of participant selection.

The focus on gaining "real", "rich", and "deep" data clearly leads to valid data (Stainback & Stainback, 1984, p. 402). A recognized threat to internal validity in this type of research, however, is that of observer effects. Firstly, there is a risk that informants will omit information, tell the researcher what they think she wants to hear, or act abnormally when being observed. Techniques for dealing with this potential limitation included multiple observations and interviews in more than one setting as well as corroboration with other informants or observers on the scene. These included family members, other patients, or hospital personnel. Secondly, concerns that responses only represent a particular point of view or that they are influenced by the researcher/informant relationship must be considered. Although there is some support for these criticisms, the data are nonetheless valid and become problematic "only if they are taken to represent views beyond that context" (Goetz & LeCompte, 1984, p. 222). Generalizability, in the conventional sense, was not the goal of this study. Rather, the purpose was to gain an understanding of patients' experience of chemotherapy in order to facilitate the development of treatment methods and interventions that respond more

specifically to the needs of patients. That is not to say, however, that the themes and categories emerging from the current investigation could not be reflective of more general social processes, however. The process by which people cope with any chronic disorder marked by an uncertain illness trajectory and an aggressive treatment regime may show similar patterns and themes.

Ethical Considerations

Ethical issues were handled in accordance with the guidelines presented by the Canadian Nurses Association (1983) and the University of Alberta (1985).

The results this study provide increased understanding of chemotherapy patients and may potentially lead to improvements in the care they receive. It was recognized that discussion of illness and treatment-related issues could cause some emotional discomfort for patients; however the investigator had graduate level training in interview techniques and encouraged disclosure of information only to the degree that participants felt comfortable. Patient welfare was maintained as the highest priority. It was determined beforehand that should information have arisen during the course of data collection that caused concern regarding a patient's health or safety such information would be reported to the Chief of Medical Staff at the Cross Cancer Institute.

In order that the role of the investigator clearly remained one of "researcher" rather than "practitioner" the

following guidelines were followed. Interview questions were open-ended and the interviewer refrained from offering advice or counselling. When situations arose where the interviewee requested or appeared to be in need of information or assistance the investigator asked permission to have the ovarian cancer research nurse contact the patient or suggested that the patient make such contact. Patients requesting counselling were referred to the chief psychologist, Support Services, Cross Cancer Institute.

In terms of confidentiality of information, the following steps were taken. All tapes were kept in the care of the researcher during data collection and the contents of all tapes were erased at the end of the study. Data was discussed only with co-professionals. Since the typist had access to identifying data she was asked to swear an oath of confidentiality. Transcripts were coded by number rather than names and in the final report, identifiable information was removed to ensure anonymity.

Interview transcripts will remain the property of the investigator. The completed report will be submitted to the library and subject to the normal regulations regarding rights to release of library material.

Prior to participation in the study subjects were fully informed regarding procedures and asked to give voluntary consent by signing the consent form (Appendix A).

CHAPTER IV

RESULTS AND DISCUSSION

The purpose of the present study was to gain understanding of the experience of cancer and chemotherapy from the patient's perspective. Four ovarian cancer patients receiving a combination chemotherapy protocol including cis-platinum were observed and interviewed in their home and in the hospital while receiving treatment.

The focus of Chapter IV is on presentation of results from the current investigation. A description of the four informants selected for the study is offered to provide a more clear context within which to examine the data. Categories that emerged from the data are defined and presented. Finally, the two integrating themes that were found to be interwoven throughout the texts are described. Quotes from actual interview transcripts are integrated into the chapter in order to enhance and clarify the results.

Description of Informants

Four informants were selected from a total group of sixteen women with similar diagnoses and treatment protocols. The investigator and the ovarian cancer research nurse were involved in the selection process. They attempted to select patients who were 'very different from each other'. Factors such as age, marital status, point in the course of treatment, and response to treatment were considered. Other factors such as geographical

accessibility and health status of patients necessarily became important. One patient who was considered early in the selection process became critically ill and was, thus, not approached. Four patients lived outside the Edmonton area and were therefore not included in the study.

The four informants were felt to be both representative of this patient population in terms of the above-stated criteria and sufficiently different from each other to offer a breadth of perspectives. The sample consisted of women aged 52, 56, 64, and 68. The age range within the total group was 31 to 71 with the average being 58 years. Age breakdown among the group of sixteen patients from whom the sample was selected was as follows: Two patients (12.5%) in their 70's; seven patients (43.75%) in their 60's; four patients (25%) in their 50's; two patients (12.5%) in their 40's; and one patient (6.25%) in her 30's. Unfortunately, none of the patients in their 30's or 40's were eligible to participate in the study. Two lived outside of the Edmonton area and one was critically ill. Of the women chosen for the study, two lived alone, one resided with her daughter and family, and one was married with an adolescent child at home. One of the informants had been employed as a nurse until just prior to the time of her surgery and subsequent chemotherapy. Similarly, a second informant worked as a retail clerk up to a few weeks before the initiation of chemotherapy. Neither of these women were working during

the time of their involvement in the study. The other two informants had not been employed outside the home for the past several years.

There was variability with respect to the informants' point in their course of treatment. Two patients were interviewed during their first and second chemotherapy treatments, one was followed through her fourth and fifth treatments, and one was seen on the day of her sixth treatment and during a follow-up examination at the hospital.

Informants were each interviewed four times, twice at home and twice at the Cross Cancer Institute. Two exceptions were notable. The first patient selected chose to discontinue the project after the first interview. She stated that her husband was opposed to her 'telling their business to strangers'. With her permission data from the initial interview were included and analyzed. Another patient was unable to meet for the final home visit because of travel commitments. Due to the qualitative nature of the study this was not felt to be problematic.

Categories

A category is defined as "a class or division in a scheme of classification" (Webster's Dictionary, 1979, p. 285). In order that categories be understood, their characteristics must be described and comparisons with other categories made (Chenitz & Swanson, 1986, p.122). In qualitative research the analysis process is directed

toward the identification of categories within the data.

In the present study the data were organized into categories in an ongoing manner. As more data were collected, new categories were derived and existing categories were subdivided. From analysis of interview and observation data six categories were derived: Support, physical response, emotional response, coping strategies, treatment expectations, and learning about diagnosis. Each of these contains several subcategories and in some cases the subcategories are further subdivided. Each category and subcategory will be described with excerpts from interviews included where they enhance understanding of the material.

Support

This category is comprised of informants' descriptions of the people, behaviors, or situations that they found to be "supportive" or helpful during their chemotherapy experience. The four subcategories identified within this category include family, friends, other patients, and health care personnel.

Family

In this context family refers to members of the informants' extended family network including husband, children, grandchildren, and siblings. Family support is defined as the offering of encouragement and help to the informant by being present during their illness and treatment or by carrying out tasks for the informant. All

informants stressed the importance of family support in their particular situation and felt that they "couldn't have made it" without their families. Statements emphasizing the thoughtfulness of family members were common.

"Like the kids are always phoning and saying, 'how are you feeling today?'"

"But they do pop in....popping in for coffee..."

"I'm lucky. I'm lucky to have them all so close."

"And so I get lots of phone calls and um - just - I don't know if it's worried as much as concerned, you know, which is really very thoughtful - certainly getting support from everybody."

The willingness of family members to assist with daily tasks was also commonly mentioned as helpful.

"H went grocery shopping for me this morning. And I mean I just gotta say, 'Do this, do that', you know. 'Could you do this?' or 'Could you?' - Anything like that and they do it. They're very good."

For the most part, however, informants described the willingness of family members to spend time with them to be the most important aspect of support-giving. One woman described this kind of support, stating, "... they can't really do too much for you. It's just - just being there - just support. 'Cause there isn't too much that they can do. You have to go through that therapy. And um it's mainly just support, just being around - answering the phone for

you, you know, and talking. Sometimes I'd lay here and my sister would sit there and we would just talk - I don't know, for hours. And then other times she would sit and read and I'd sleep, you know. It's just the idea that somebody's there. You don't have to do anything, you know. You don't want somebody you have to entertain 'cause you're uncomfortable - 'cause you don't feel like you can get up and do anything. So it's mainly, I would say, just support and not fluttering around them, you know, making them feel like a patient. And - like with me all I felt like doing was laying down - so just quiet support...Must be hard on anybody that hasn't got a family now I can see. Not, like I say, physical help you need. It's just somebody being there."

Friends

Included in the subcategory of friends were co-workers and people outside the family network with whom the informant would socialize. Support from friends most often took the form of phone calls asking how the informant was managing. Although informants stated that they had not changed their involvement in social activities since becoming ill there was a notable decrease in their desire to visit friends at times when they were feeling unwell. One woman described feeling "overwhelmed" by company and frustrated with being asked to repeat her "story" over and over. Another stated that she told her friends not to come and visit until at least a week after her treatment.

"... With me it had to be family. I didn't want to see visitors. I didn't want anybody to come and see me...So support people have to be somebody that - family or somebody you're very close to so that they can do your own thing and you feel comfortable."

Other patients

The informants' description of other patients included those people who they met or observed while in the hospital on the day of their chemotherapy treatment as well as those who they encountered in other situations who had received or were currently receiving treatment for cancer.

Informants stated that they occasionally visited other patients on the day of their chemotherapy treatment and that these visits were helpful both in terms of making the time pass more quickly and in obtaining support from "someone who really knows what it's like".

"It just depends on - there was a lady in before and we had a chat and another time um actually there was a girl from X and we chatted most of the day. I found a great deal of help from her because she had gone through it and um you sort of got it first hand. But other than that some, you know - sometimes somebody comes in and you say hello and you don't know what they feel like - if they're gonna' chat back or not."

It was the investigator's observation that the informants engaged in very little socializing during their day of chemotherapy treatment. For the most part they

appeared to remain on their bed either reading, knitting, or sleeping.

Another source of support for the informants arose out of their encounters with people who had received treatment for cancer in the past. Hearing about the experience of others and particularly of "success stories" appeared to be particularly encouraging and is illustrated in the following comment, "She brought me a flower but the big thing was she said, 'Hey J, I've had it twice.' And she said, 'Here I am.'...I said to her later, I said, 'I don't think you realize what that did'. You know, it's hearing other people - because you read in the paper and everybody is dying of cancer and um that's all you hear."

Health Care Personnel

The subcategory of health care personnel includes the doctors, nurses, dieticians, and technicians involved in providing consultation and care to the informants. Informants identified the nursing staff as the health care personnel who offered them the most support throughout their treatment experience. They were observed to interact in a relaxed manner with the staff and appeared to develop a particularly close relationship with the ovarian cancer research nurse. Their comments of praise for the nurses were frequent.

"I think (the nurses) are wonderful - very, very nice. They're all nice...When I come in I know exactly what to do now."

"The girls up in the Day Care are super, just a super bunch of girls."

"They're a good crew. They look after your every need and if you needed something I imagine all you have to do is holler and they're there Johnny-on-the-spot."

Other members of the health care team were seldom mentioned in the context of support-giving. This lack of mention seems noteworthy. It was the investigator's observation that although patients reported being generally pleased with the medical care they were receiving, in informal conversation they were frequently unable to recall their doctor's name and seemed confused about who was monitoring which aspect of their care. This could be related to the large number of specialists involved in their treatment.

Physical Response

All informants experienced physical side effects as a result of the chemotherapy treatments. This is consistent with research findings examining the impact of chemotherapy as well as with expectations of medical personnel related to the specific combination chemotherapy protocol these patients were receiving (Meyerowitz et al, 1979; Barber, 1980; MacLean, 1986). Although there were some personal idiosyncracies with respect to physical reactions to the treatment all informants reported difficulties with nausea and vomiting, fatigue, and hair loss. Each subcategory is described below.

Nausea and Vomiting

The informants were united in their identification of nausea and vomiting as the most distressing physical side-effects of the chemotherapy. There was, however, marked variability in the observed and reported frequency and duration of the symptoms as well as in the informants' description of their subjective experience related to the symptoms. For some the experience of nausea and vomiting was almost unbearable.

"I just make it until home most afternoons - then I get sick...The first couple of days is quite bad. I don't eat because I know when I eat it comes all up anyhow. And it feels like it seems to come up from here (points to lower abdomen) and sometimes it's dry. Oh my it hurts. Like it hurts your whole belly, like you know. After that I shake - I'm shaking all over - can't stop shaking."

"I didn't eat a thing for 4 days so I guess - but even days when I go to the bathroom at night and I'm throwing up I don't bring up anything. I'm always heaving. You know at least if you're - if you're actually sick - you're bringing up something and you know what you're doing. But this way it's just a constant heave and it - it does hurt."

Other informants reported the symptoms of nausea and vomiting in a much more matter-of-fact manner.

"I just feel as if I'm going to (vomit). It's mostly when I go home - on the way home sometimes I bring it up. They say it's only natural."

"Oh well I was a little bit nauseated, you know, when I came home. I tried to hold it in the taxi and when I came home I started - I just brought up, you know, a little bit - not very much. And after that I was a little nauseated but I take Maxeran. Maxeran and that cuts the heaves down - but I expect it you know."

-Fatigue

Symptoms of fatigue and lack of energy were also distressing to the informants. All of the informants had been very active prior to their illness and were forced to alter their daily activities in response to their reduced energy level.

"I'm kinda tired. Most of the time I'm tired. I start to do something - like, you know, in the morning I wake up and think about the day - 'I'm going to do this, or I'm going to clean this, do the windows, like you know. Well, then I have to stop, you know, and all of a sudden my strength is gone and that's it for the day. That's it...It bothers me too."

"Well I don't have near the energy. I think a certain amount is lack of exercise...When you're not doing anything you lose a great deal of energy. But I don't have the zip."

Sleep disturbance was also common, particularly on the night before scheduled chemotherapy. Most patients took a mild sedative to help them sleep.

"...but when I go for my - like when I have to go for

my chemo I can't rest."

"Like last night I couldn't sleep very well. I was awake thinking about coming down here, you know."

Hair Loss

All informants experienced hair loss as a result of the chemotherapy. Those who were early in their course of treatment were just beginning to lose their hair at the time of first contact with the investigator. Those further along in their treatment process were starting to see growth of new hair. All informants had purchased wigs. Some chose to wear scarves when they were at home.

For most informants hair loss primarily presented a practical inconvenience. They reported being bothered by hair flying around, hair all over the furniture, hair in their food.

"... Not the fact that I was losing my hair but hair falling out. It was just driving me bananas, you know. I'll be kind of glad when it's all gone because the worst part of it is the hair flying around everywhere...Maybe I'll cut it all off."

This pragmatic attitude was further exemplified by the response of one informant when asked if the experience of hair loss was difficult for her.

"Not really. I knew it was coming out so - and I mean at my age - but I just - well, I wear a wig."

There were some informants, however, who found the loss of their hair to be distressing emotionally,

associating feeling good about their hair with personal attractiveness and femininity. One woman stated that although hair loss was 'not one of the most difficult things' associated with the treatment she didn't like her husband to see her without her wig. Another reported much greater distress related to this side effect, describing her feelings in the following statements.

"That's one of the worst things, I think, is losing the hair. Yep. And then, you know, as a woman you think, 'How does your husband look at you - like, you know, when you don't have hair?' 'Cause it's strange for him too. I think about it quite a bit...That's very hard. That's one of the hard things. Well a woman is - one of a woman's assets is her hair, isn't it?"

It may be important to note that the informant quoted above was in an unstable marital relationship at the time of the interview and separated from her husband shortly thereafter. It could be speculated that anxiety regarding the relationship generally might be manifested in increased concern about issues related to personal attractiveness.

Emotional Response

All informants experienced some degree of emotional distress as a result of their illness and treatment. Their emotional response to the experience of receiving chemotherapy covered a wide range of negative emotions. As with the physical responses, subjective differences were noted in informants' descriptions of their emotional

responses. Four subcategories were identified within this category. These included fear, worry, frustration, and embarrassment.

Fear

Fear represented the predominant emotional response for all informants. The range of fears was diverse, including fear of concrete matters such as tests and procedures as well as more abstract and existential concerns such as fear of the unknown.

Informants reported feelings of apprehension related to the effects and side effects of the medications they were receiving. With one exception they remained compliant to their medication regime, however. The exception involved one woman's substitution of an over-the-counter antiemetic for that which had been prescribed for her. She felt that the prescribed medication was not effective and had too many side effects. The following comments describing fear of the drugs and their side effects were typical of those presented.

"Well there's a certain amount of fear involved cause you know that the chemicals you're getting are also destroying so many other cells. And the side effects. There's so many. I think - so there's always that underlying, you know, fear."

"You know, you just keep wondering, they keep pushing these drugs and there's no drug that doesn't have a side effect you know."

Fear of possible disease progression was indicated by the comments of the informants. New symptoms or problems often caused concern about the spread of malignancy or the possibility that the treatment was not working.

"Still, I wonder if it's a new one (tumour) in the abdomen since the radiation."

"... In the back of my mind I kept wondering if the cancer was starting someplace because it was - I just felt that something was causing it (inflammation)...and I couldn't figure it out and then you imagine that maybe it isn't working like it should and um that maybe, you know, it is developing further. You have a great deal of doubt."

The procedures related to the treatment itself were a source of anxiety and apprehension for the informants. They faced monthly blood tests and intravenous injections of chemotherapeutic drugs plus physical examinations, scans, x-rays, and the possibility of a second surgery. Comments describing a general fear of the chemotherapy day with its concomitant procedures were common.

"Well, the day before (chemotherapy) I get totally nervous and make myself sick because of the nerves. That's why - I am a nervous person to start with and I make myself sick. I get a headache, you know."

"To tell you the truth I'm terrified every time I go down (to the hospital). Yeah, because I don't know what they're gonna do next - what it's gonna be like and um yeah...I mean the chemo did help me. I recommend it right

there. But I'll tell you I was scared every time I went down there."

Informants also described concern and fear that they were not responding to their treatment in a 'normal' manner. Although they worried that they were reacting atypically or abnormally to the medication they expressed some reluctance to contact health care personnel and tended to 'wait it out' until their next appointment or until they heard from the nurse.

"... I just felt zonked. I felt as if I had taken a sleeping pill. I was that tired. And I lay down and sleep again and that worried me. Anything that's that abnormal scares you and then you doubt anything that they said."

Reassurance that their reactions were not abnormal was clearly helpful in reducing the anxiety level of the informants as is exemplified in the following comment.

"And it seems like I'm always pushing myself and all I want to do is lay down. So when (the nurse) told me I was at my lowest ebb, well then I felt better. I thought, 'well it's natural.' I thought it was just me. I was wondering if it was me psychologically or whether it was, you know, or whether it was natural - but I guess it was natural."

The treatment period was marked by uncertainty and fear of the unknown. Informants were unable to anticipate predicatable phases of response to chemotherapy and were, thus, anxious and fearful about what might lie ahead for

them. Strauss (1984, p.65) described the difficulty associated with uncertain disease trajectories, noting that daily activities and social arrangements are upset when the course of illness is uncertain and unpredictable. Informants' statements are similarly reflective.

"It's just that you DON'T know. You're not absolutely sure. You think - with other things like just plain surgery it's a matter of getting over it and going back to work but this here is indefinite. They tell you they're sure you're going to be OK but nobody knows for sure until the surgery is done. You know, it could involve follow-up—treatment you know."

"It's not knowing how long it's gonna last that wears you down. If it's gonna last for a week like that well, yes, get someone to pull the plug, but if um you know it's gonna be one day then you might be able to say, 'Well we can handle it a little bit better'. I don't know."

A more generalized fear of the future was reflected in the following statement by an informant near the end of her first series of treatments.

"And, you know, periodically you'll have days that you keep wondering, 'What if...?' You know."

Worry

Worry is defined as "to feel or express great care or anxiety" ([illegible] Dictionary, 1979). A major source of worry for informants was related to their concern about family members worrying about them. This circular

situation was well-illustrated in the following comments.

"Oh, sometimes you feel like you want to explode. Like the kids are all calling. They want to know everything. You've been trying to explain to them but um you don't - like I can't call the kids up and say, 'Gee I'm having a rotten day', you know. Because then automatically they think that the chemo is not working and they worry and I don't know. My mother was beside herself and she's had two heart attacks, you know. I was worried about her. And my mother-in-law was so worried...so we made the trip really for their reassurance..."

Other comments indicated that these women worry about upsetting or imposing upon their family during their illness.

"I know, even though I've told the kids, you know, for instance about the emesis on the first day - the last two times my youngest son has been picking me up and I know he's just scared out of his tree. He's worried sick. And I can say, 'Don't worry about it. Just keep driving and if I have to throw up, just let me throw up. It's just all part and parcel.' But it really upsets them."

"But I know the children worry so much about me. That is what bothers me as much as anything. Because, you know, they are at work...I know it upsets them when I'm sick and they have to go home. But it's not always convenient for them...It disrupts their lives and I don't like that, you know."

A more general worry about the outcome of treatment and a recognition of the underlying worry related to the stress during the treatment period was expressed in the following.

"I think the biggest worry is, you know, 'Is chemo going to cure the - kill the remaining cells?' I think that is the big thing. um. Probably the stress to come in once a month. I don't try to think about until two or three days before but still I think there's an awful lot of underlying stress in your subconscious that you really don't think about a great deal."

Frustration

Informants expressed frustration at their physical limitations as well as at the medical staff.

"Well I wish in one way I could get around like other people. Some days you know I get down - right down and out to tell you the truth. And I see these people going out and going here and walking. I just think, 'Why - why can't I do it?' You know."

"I see people doing things - like, well my sister's a little younger than me but to me she has SO much energy. It frustrates me." (tearful)

"I don't know who I'd go to if I did want to do a little screaming and yelling. And that's frustrating. Your hands are tied. You feel as if they've taken you and you're sort of pushed in these slots and you don't have options. And that's the problem."

"You go through a stage where you feel that the doctors aren't being straight with you."

Embarrassment

Diarrhea following chemotherapy was cited as the most embarrassing aspect of the treatment process. The attacks were both uncontrollable and unpredictable making them particularly distressing for patients receiving their first treatment.

"It's the after-effects. And the last time I was there it went through me - like diarrhea. And I was a mess. And it's embarrassing. And I don't know if it will do the same thing this time or not. I haven't any idea."

"You can't do a thing about it and it's embarrassing." (diarrhea)

Coping Strategies

Coping has been defined in a number of ways by numerous disciplines including biology, sociology, and psychology. In the present context it is defined as "the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984, p.283)." This definition emphasizes that coping is a process not a trait or style and that coping activities are directed at management of stressors rather than at mastery, recognizing that many human problems including terminal illness cannot be mastered but, rather, must be redefined, tolerated, endured, or accepted (Lazarus & Folkman, 1984, p. 283). It

is also important to note that this definition does not assign positive or negative value to various patterns of coping. That is, unlike traditional definitions, particularly those within the psychoanalytic orientation, certain strategies are not associated with 'good coping' and others with pathological or 'poor coping'. The following subcategories were identified within the informants' descriptions of the strategies they utilized for managing the stresses they experienced as a result of their illness and treatment. A distinction between 'problem-focused' and 'emotion-focused' strategies was evident and they are, thus, grouped accordingly. Problem-focused strategies include "efforts at doing something constructive about the conditions that harm, threaten, or challenge" (Lazarus & Folkman, 1984, p.284). Subcategories of Information-seeking, Isolation, Distraction, and Taking Control are included here. Emotion-focused coping refers to "efforts directed at regulating the emotion itself" (Lazuras & Folkman, 1984, p.284). Strategies of Comparison With Others and Hoping were identified as emotion-focused subcategories. It is recognized that the same strategy can serve both problem-focused and emotion-focused functions.

Information-seeking

The majority of informants sought to lower their levels of stress by increasing their knowledge regarding their disease and plans for treatment. For some this

involved searching out library references. For others, information was gained through direct questioning of medical personnel. The following examples indicate that this strategy was perceived as very useful by some informants who felt somewhat comforted by the information they gained.

"In the beginning when I talked to the doctor here and to the nurse like this I came down and talked to her. I came down for a talk and to me at the time I thought I would be more like a guinea pig like, you know, using people as guinea pigs but I have read up quite a bit at the X library. They have quite a few books about all this. And I've read up about this quite a bit and I don't think that it's altogether true like, you know, what I was thinking. Oh I know I'm never gonna get old but um well they're trying to do their best; I can see that you know. That's all I can say because that's all anyone knows about it so..."

"I like to know. As a matter of fact I asked my gynecologist exactly where it was because I really wasn't sure. It's much better to know what's - you know - what's what rather than wondering."

Not all informants found the strategy of information-seeking to be useful in alleviating their anxiety. In fact, the following statements seem to indicate the converse.

"Sometimes I wish I wasn't (a nurse) (chuckles)

because you tend to grab your books and read and you always imagine the worst you know. It's never just a simple this or a simple that. You imagine the worst. I don't know if it has really helped me a great deal other that you know it does help you understand the drugs that you're getting sort of thing. But sometimes lack of knowledge isn't all that bad (laughing) for the emotional side you know. Sometimes when you know what's going on it's not necessarily helpful. I think you find people that aren't really aware of a lot of the things and they, you know, just take God's words from the doctors and 'OK this is going to happen and that's going to happen and OK and um don't question it. I find myself, doctors aren't infallible."

Isolating

Informants sought to be alone during the times when they felt particularly unwell. Opportunities to be in the company of others were postponed until the patients felt able to be more actively involved in socializing.

"I guess I really don't want people to see me at my worst...I tend to - when I'm not feeling good I tend to want to be isolated. I've had friends that have phoned and said they'd come to sit with me for the day and I said, 'No'...I want to visit them when I feel good and enjoy their visit. I really don't want to visit when I'm gagging or nauseated or that type of thing, you know. I'd just as well shut the curtains."

"I'd rather be alone like, you know, for a couple of

days anyhow, yes. Suffer by myself. Even when my daughter comes I tell her, 'Just for the first couple of days don't bother'. First of all I'm not feeling too well and I don't feel like company and second of all, they're smokers and I don't smoke and then they get smoke in the house and it bothers me so."

Distraction

Informants adopted many strategies for distracting themselves from the distress of their symptoms and from worrisome thoughts. Their activities were both cognitive and behavioral in nature. Cognitive-type distraction strategies
are illustrated in the following examples. That is, informants attempted to direct their thoughts in a stress-reducing manner.

"... There are certain things that you do have to shut out...Do something about the things that you can and the things that you absolutely can't change you can't worry about them or dwell on them."

"I would just try to get onto a train of thought that was, you know, constructive - like what the family was doing."

Other comments describe informants' efforts to cope by becoming involved in physical activities that distract them from their stressors.

"...get outside, paint the fence, work in the flowers and get a bunch of sewing done. So I'm constantly keeping

busy. I don't like to let these things bother me. I try to keep my mind off it. I jump in the car and go someplace or go out in the garden or sew a couple of dresses."

"And I watch for my mailman at 2:00, you know, to see if I get any mail. When I get down in the dumps I just pick something out of the fridge and munch on it."

Taking Control

Informants were involved in a variety of activities that appeared to be 'self-prescribed aids' for adjusting to their situation. Although the specific coping activities under this subcategory were very different they all served to enhance the individual's sense of personal control. Examples of informants' comments are illustrative of their need to feel in control whether or not their actions are recommended or condoned by medical personnel.

"I just don't take a lot of the pills that they prescribe for me because they DO make me sick."

"I like - I think why I sleep so well at night - I like my rum and coke. I have a couple of those at night and 9 times out of 10 I can drift right off."

"... It's reached a point where I've decided maybe I'll do what I think is best for a change...Because frankly I - you know, sometimes I don't - I'm losing confidence in them."

The following example describes one informant's attempts to decrease the worry her family experiences.

"... I always make a point - first thing I do is get

up and put my make-up on. Well, I've gotten used to that, mind you, but basically because I want them (family) to feel secure and that I am feeling pretty good. I think you do it for your family. Because, you know, I know that my husband worries sick and this way, you know, he's certainly more relaxed."

Comparison With Others

The strategy of comparing self with others was widely used by informants. This emotion-focused strategy served to alter the way in which they percieved their situation. They compared themselves to other patients as well as to other groups of people under stress.

"Well I talked to the people that had it (chemotherapy) every day and I really don't know how they cope with it, you know. I could see them throwing their hands up."

"I always say 'There's people worse than me - that's had a harder time than what I've had.' You know, when you see some of the things that's happened on TV you think, 'It could be worse.'"

The following statements indicate that this strategy serves a useful purpose in helping patients gain a more optimistic perspective of their situation.

"But you know people have had it a lot rougher than me. A lot of people - people who have had to cope with raising a family and feeling sick...With me, if I don't feel good I can just lay down - big deal, you know. You

look at it that way. And then there are people more worse off than you. I think that's the philosophy that you have to take if you're going to um - going to look at it realistically, anyway. Because you can wallow in self-pity if you want to - some people are that kind...You look at the other side of the coin - just how lucky you are...You look around and you see people worse off than you are and it's sort of a therapy. This girl I work with - she has it. I think there is a lot of therapy to the patient when you see people that are worse off than you are - children and young people and ..."

Hoping

A second emotion-focused strategy involved utilization of hope to cope with worries and difficulties. Informants' expressions of hope ranged from a speculative statement accompanied by the superstitious crossing of fingers to more definitive and positive expressions of hope and belief that the present situation will improve.

"And I hope everything is alright. I hope - (crosses fingers) my scan went good - that there was nothing on my scan."

"And you don't know how much you can stand until you have to. And um and you know that it's not going to be like this all the time. You're going to get better. Like the first time as I said I was really sick. Now this time wasn't bad, you know - not feeling good but not um it's not devastating - but just feeling like you've got the flu -

but you know it's going to get better...And you look - you don't look for today. You look - 'two days from now I'm gonna feel better' - you know. This idea keeps you going."

"I always had hope. Yep. I can't say - even when they told me in the hospital I can't say I was - I was shocked - but I had hope."

The researcher asked informants to identify coping strategies that they felt did not work or were not useful to them. Among this group there was a general inability to identify ineffective strategies.

Treatment Expectations

All informants approached the treatment process with some preconceived ideas of what the experience would be like. Their ideas came from information gained from the medical and nursing personnel who explained the treatment regime and from family and friends who had previously received chemotherapy. This information was utilized to weigh the risks and benefits of chemotherapy and ultimately to make a treatment choice. As they moved through each subsequent treatment informants' store of expectations increased. Their attitude toward the upcoming treatment day was influenced by their response to the last treatment as well as to their understanding of what procedures they would face.

Risks vs Benefits

Informants indicated that their consideration of treatment options was limited in that they felt

chemotherapy was really their only choice. The following statement indicates the use of 'statistical' information to assist in decision-making.

"Given the chances - the doc said about 80% chance that I can get it under control. I suppose one would be a damn fool if one didn't try."

Other informants relied on a more personal or subjective method, relying on positive accounts from previous patients.

"...I have great faith in chemotherapy. I've heard of different ones...I really didn't stop to give it much thought. I thought, 'Well, that's about the only alternative' because the doctor said he didn't think surgery was the way to go in my case...You just didn't have any other choice, you know."

Anticipation

Informants' expectations of the upcoming treatment day were influenced by their response to the prior treatment. All of them marked off the remaining time and either dreaded or welcomed their return to the hospital.

"...I really did dread going back this last time. I don't know. I - you know. As soon as I saw the hospital I said to my husband, 'God I would like to turn around and walk the other way. I really would (chuckles)...I said to him, 'I just - I just dread today.'"

A much more optimistic attitude is presented in the following comments of a woman during her second

chemotherapy treatment.

"I guess I was kind of anxious to have them.(treatments) So I was kind of anxious to get this one over with because I don't expect to be as sick as I was last time and I'm kind of anxious to see how I handle it. I know I have to have it anyway so - but I was sort of looking forward to it, you know. And then you see when I have all three well then I get my scan and so I will be looking forward to the third one too because that's when I - when my scan is - to see what happens."

Learning About Diagnosis

The present study attempted to focus on patients' experience of illness and treatment. Although there was no effort to directly assess the informants' feelings and responses at the time the diagnosis of cancer was made, it became clear to the investigator that this was an important issue to the patients. It appeared that the manner in which the diagnosis was presented made a significant impact on these women and subsequently influenced their experience of treatment. The diagnosis of cancer came as a shock to most patients. Some had been symptom-free prior to diagnosis and others had attributed their difficulties to other causes such as ulcers or strained abdominal muscles. Informants described the announcement of the diagnosis as very traumatic.

"Well I was stunned. Because all along my own doc said, 'Don't worry. There's no cancer. There's no sign of

cancer. Don't worry about it.' And then when they did this exploratory and they found the cancer I was stunned to say the least. I couldn't believe it. After them – both doctors telling me."

Informants reported feelings of anger related to the manner in which the information was conveyed to them. One woman was particularly distressed by the way in which her doctor communicated the news of her diagnosis to her.

"I went through a trauma. I went through a very bad time of course when I found out, you know. Because at that time I had a different doctor and he just told me up front without even my husband who was sitting in the waiting room. I was in the other room with the doctor and he just told me abruptly, 'You're gonna die' like that, you know. And I looked at him, you know. And he says, 'that's it.' He says, 'You got a big tumour', he says, 'It's cancer', he says, 'Most likely you're going to the hospital, you won't come out.' Now first of all I thought it was very abrupt and rude because he should have asked my husband to come in and talked to both of us. When the man was sitting there he could have asked him to come in. I didn't think he treated it right at all. Of course I went into shock. I was in shock because, you know, you get it told just like that, you know."

Another informant perceived that her interpretation of the doctor's words and actions may have added to her distress.

"...When I went in there - I had never known the man before in my life. He's 65 years old. And he checked me over and then he wrapped his arms around me and hugged me - and to me that - not knowing the man - to me that was like the kiss of death. As if he was saying, 'Look kid, you don't have much time.' And that was MY impression...But it's the way they say things. You're in a position that you're trying to catch everything they say...They called it a cyst but I knew it didn't look much like a cyst - so I wasn't all that shocked, but it was when he draped himself around me that I thought, 'Oh oh, it's curtains'. It's the way you interpret things."

Ambiguously presented information was also difficult for patients' and their families to deal with and served to increase fear and frustration. The following example illustrates this problem.

"He rattled it off so fast. He just said, 'you have to go to chemo and then we'll do surgery after and bye I've gotta go...He said to (husband), 'your wife has a cancerous tumour' and X said, 'What happens now?' He said, 'Well I didn't mean that she would ONLY last for 6 months' and X thought he meant maybe 6 months but not much more and he was going absolutely crazy."

It is clear that the presentation of diagnostic information represents an important component of the treatment process. Ambiguous information, inappropriate presentation, and misinterpretation of verbal and nonverbal

messages all served as sources of distress for informants.

Themes

Theme is defined as "an integrative principle, a mechanism for unifying the parts of a whole" (Opler cited in Coreil, 1978, p.10) It represents the "main concern or problem for the people in the setting" (Glaser, 1978, p. 94) and reflects the essence of the data. Results of the present study indicated that, from the informants' perspective, there were two main themes that reflected their experience of illness and treatment. These two inter-related themes described the experience of receiving chemotherapy as one of 'biding time' and as 'negative but tolerable'.

A theme of 'biding time' consistently emerged from the data. Informants described living from treatment to treatment, scan to scan, surgery to surgery. Their current situation appeared to be one of enduring the negative effects of chemotherapy in hopes of a positive outcome. At the same time, however, there was recognition of an uncertain future and planning was generally limited to vague ideas and possibilities rather than concrete goals. This paradoxical situation whereby life was perceived as 'on hold' for the indefinite period of time of the treatment process and also uncertain in terms of long-range outcome appeared to be particularly stressful for this group of women.

One woman described her feelings of being on hold

during the treatment period in the following statements, "You're just sort of biding time. But I imagine after it's over well then you can go back - you'll feel a lot different - able to handle things...So I imagine I wouldn't have any trouble filling up my time once I get this finished with. Then I can get at it...I suppose maybe you have to cultivate patience. You know. You can't look at tomorrow. You've got to look at 6 months - a year from now." It is evident from these statements that she sees herself as 'biding time' until the treatment is over and her life returns to 'normal'. Evidence of the paradox emerges, however, when the same woman later makes the following comments:

"So we'll just see. I'll just take one step at a time...Like before any of us got sick, you know, you're planning, 'We'll do this or do that next year' and all that. But, you know, that kind of changes. You figure, 'Well I can't plan too far ahead 'cause you don't really know. It's just as well, you know - just as well not to build too much. Take it as it comes. I think it's the best way...I don't plan too far ahead. First things first."

During this time informants described finding it difficult to accomplish things or undertake new tasks.

"You almost feel like you're marking time. I think, 'Well there should - I should get busy and do something. And I don't. You know, just sort of - I was thinking the

other day - I'm just sort of sailing in space - just sort of waiting for the next development or waiting to see what happens or something like that, you know."

Another informant clearly describes the difficulty of not being able to take one day at a time and at the same time feeling unable to make plans for the future.

"It's just that you'd like to forget the whole damn thing and um and think 'wouldn't it be great if I could take each day at a time?' I find that I'm not planning. Like for instance with the summer - with going to Expo - I said to my husband, 'I'm just not in a position - I guess I just want to get this all over first.'"

Related to this is the second theme of experiencing chemotherapy as 'negative but tolerable'. Although all informants found the treatment process to be both physically and psychologically stressful they remained hopeful about the outcome and adopted a number of coping strategies to help them manage their situation. The following statements are reflective of the paradox within this focal theme:

"I mean the chemo did help me. I recommend it right there. But I'll tell you I was scared every time I went down there."

"So, you know, I just felt that um that there was no option and that was my only choice. And I know some people - I heard a lady in there one day saying that she was going to refuse chemo - that she really didn't care if she died -

she was going to enjoy, you know, her life - whatever she had left...and that really bothered me...I just feel that there is a hope of doing something about it. But I'm going to go down fighting. And I'm not going to - I'm going to take every chance I get."

Summary

Findings of the present study are consistent with those in the current literature that suggest that chemotherapy negatively influences the quality of patients' lives (McArdle, et al., 1981; Meyerowitz, et al., 1979). Levels of subjective distress varied considerably among subjects. They employed a number of coping strategies that appeared to enable them to manage their situation. They experienced the treatment period as one of 'biding time' or 'living on hold'. At the time of final interview all four informants were continuing with their treatment regime, indicating a general willingness among patients to tolerate the negative effects of treatment in order to realize the potential therapeutic benefits.

CHAPTER V

SUMMARY, CONCLUSIONS, AND IMPLICATIONS

The purpose of this study was to gain an understanding of ovarian cancer patients' experience of treatment. The questions that guided the investigation were: 1) How do ovarian cancer patients experience their treatment? That is, what does it feel like, physically and emotionally, to be receiving aggressive anti-cancer drugs? 2) How do ovarian cancer patients receiving chemotherapy perceive their treatment? That is, what do they think about their treatment and how do they conceptualize it? 3) What coping strategies do ovarian cancer patients currently utilize to cope with their illness and treatment? What is their perception regarding the effectiveness of these strategies?

Exploration of these questions took place via open-ended, semi-structured interviews with four ovarian cancer patients on a combination chemotherapy protocol including the drug cisplatin. Patients were interviewed in their homes as well as in the hospital over the course of approximately six weeks during their series of monthly chemotherapy treatments. Interviews were tape-recorded and transcribed verbatim. Analysis of the transcripts was directed toward identifying coding categories and themes within the texts.

In this final chapter, results of the study are reviewed and discussed category by category in light of

current research findings in the areas of psychosocial oncology and coping. Implications of the current findings for clinical practice as well as recommendations for further research are presented.

Summary and Discussion

Support

This study found overwhelmingly that patients depend on their family members for support during their illness and treatment experience. Although they stated that friends were also important, it was clear that their friendship network offered far less day-to-day support than did their family. Patients tended to extend their activities to include socializing with friends only when they were feeling well enough to be active participants in the interaction. Families, on the other hand, were called upon to be present even when patients 'just felt like laying there'. This is in contrast to Lindsey, Ahmed and Dodd's findings (1985) among their American sample in which patients ranked friends as providing most support. It is more in line with what they saw among their Egyptian and Swiss groups, namely, a stable and supportive family network. The informants' age and marital status may have been influential factors in this area and must also be considered in the discussion of support dynamics. Informants in the present study were between the ages of 52 and 68. In terms of developmental stage, this is a time when it is expected that involvement in employment and

social activities might decline. It is also notable that two of the informants were widows. Previous studies have shown that this subgroup tends to view their children as most supportive (Smith et al., 1985).

Perhaps related to this dependency on the family network was the observed and reported lack of involvement with other patients. Although those who had had contact with other patients reported benefits from the experience there was little effort to initiate relationships with co-patients in informal conversations and no attempts to become involved in patient support groups. Again, it may be speculated that age is a factor, supporting Fobair and Mages' findings (cited in Novotny et al., 1984, p. 34) that older patients tend to have more difficulty becoming involved in new activities. Lack of information and encouragement from professionals may also contribute to this hesitancy.

Finally, nurses played an important role in providing support to these patients. They were seen as the main source of information related to symptom management, were called on to assist with instrumental tasks while patients were in hospital, and were clearly supportive to patients emotionally. Patients commented on their helpfulness and cheerfulness and referred to the nurses by name. This did not appear to be the case with other professionals. As stated in Chapter IV patients were noted to frequently become confused about which doctor was 'in charge' of what

aspect of their care. This may be related to the fact that most of them had been referred by their general practitioner to an oncologist, then on to a surgeon, and back to the oncologist with day-to-day management provided by their general practitioner. In addition, they were likely seen by residents and/or interns while in the hospital. It is not surprising, then, that these patients became much more familiar with the nurses on the unit and looked to them to meet their ongoing management needs.

The physician's presentation of diagnostic information had a profound impact on patients, however. This situation is always distressing and frequently results in lasting psychological trauma to patients. It is an area that has received little research attention, yet appears to be extremely important to patients' adjustment.

Physical Response

Patterns of physical response to treatment effects and side effects in this group were found to be similar to those found by other investigators. That is, nausea and vomiting were very common and perceived as most distressing. Variability between patients was notable. Hair loss appeared, for the most part, to present a practical problem to these patients. Notably, the two patients who did express concern about hair loss in terms of altered body image were married. The first woman who was in a supportive relationship reported that although hair loss was among the least of her concerns she did not

like her husband to see her without a wig or scarf. The second woman described losing her hair as 'one of the worst things' and expressed fear regarding how it might affect her husband's perception of her. Fatigue was described by all informants as a distressing side effect, leading to concerns regarding their 'normalcy' and the effectiveness of the chemotherapy and to frustrations at not being able to maintain previous levels of activity.

Emotional Response

Informants in this study indicated emotional responses of fear, worry, frustration, and embarrassment. These subcategories arose from the interview texts and represent the actual words used by the patients. They are not terms commonly found in the literature to describe the psychoemotional factors influencing patients. Anxiety, depression, and hostility are those constructs most likely to be assessed by researchers. The measurement of these constructs usually involves the administration of a particular instrument or the application of certain criteria. It may well be that the experiences described in the present investigation as fear or worry actually fit with what has been previously defined as anxiety. It may also be the case, however, that in other studies patients' experiences have been made to fit the criteria or operational definition of anxiety in order to meet methodological limitations. Similar concerns arise regarding the measurement of depression. Although

informants in this study reported feeling 'down' occasionally none of them described themselves as depressed. Symptoms of low energy, sleep disturbance, and appetite alterations were common, however. Application of usual criteria for measuring depression would include these symptoms, which are recognized as effects of the illness and treatment, and may result in an inaccurate diagnosis of depression.

Coping Strategies

Informants employed a wide variety of strategies that fell within the six categories of information-seeking, isolating, distraction, taking control, comparison with others, and hoping. These would appear to fit within Lazarus' (1980) broader conceptualization of problem-focused and emotion-focused coping. That is, information-seeking, isolating, distraction activities, and taking control strategies were directed toward actively altering the situation whereas comparison with others and hoping were attempts to change the meaning of the situation as it existed. The tendency for all informants to compare their situation with that of others perceived as worse off is consistent with Taylor's findings (1985). She noted that this strategy was useful in assisting patients to bolster their sense of self-esteem. It would appear to have served a similarly beneficial function for the present sample.

Informants had little difficulty describing their

coping activities but were limited in terms of their ability to evaluate the differential effectiveness of various strategies. With the exception of the one informant who noted that, at times, seeking information about her medical status led to increased anxiety, patients were unable to identify strategies that were not helpful. They tended to perceive all strategies as helpful. This finding may have implications for those involved in designing educational programs and may contribute to the difficulties that seem to arise when professionals attempt to teach 'good' coping strategies.

Cognitions and Treatment Expectations

Informants entered into and proceeded through their series of treatments with definite preconceived thoughts about what the experience would be like. They based their ideas on past experiences with other patients and on their own increasing store of information. It would seem that Zook and Yasko's (1982) finding that patients with a negative past experience with someone on chemotherapy were likely to be negatively influenced might be supported by this study. That is, comments such as 'I watched X go through hell with it and I'm not too keen on it myself' or 'I've heard of different ones who've had it and done real well' would be expected to influence patients reaction to treatment.

Patients tended to enter each subsequent treatment with an idea of what it would be like. This expectation

was not necessarily realistic but clearly served a function in helping patients cope with their situation. They usually framed their expectation in a positive way, indicating the important role of optimism and hoping in dealing with uncertainty. For example, after a particularly bad month patients seemed inclined to expect that 'this treatment has to be better'. If the side effects had not been too difficult in the past weeks it was expected that 'things should go smoothly this time too'.

Themes: 'Biding Time', 'Negative But Tolerable'

Two interwoven themes emerged from the data to describe the informants' experience of chemotherapy. The first was a theme of biding time. That is, informants felt that they were 'on hold' during the treatment process, postponing activities until the completion of their regime. Since the outcome of treatment was uncertain and the need for further chemotherapy following a second look surgery a possibility, patients described the paradoxical situation of holding everything until the current series of treatments was finished and feeling they should be living day by day and not counting on the future. Clearly, the experience of illness and treatment markedly influenced the way in which these patients perceived and interpreted the meaning of events temporally.

The second theme described the experience of treatment as negative but tolerable. Although all of these women experienced negative side effects of chemotherapy they

remained optimistic about its benefits and remained compliant with the regime. Similarly high rates of compliance in patients with high levels of treatment side effects have been noted by other researchers (Taylor et al., 1984).

Limitations of the Present Study

Coping is a dynamic and transactional process (Lazarus, 1982, p. 163). The current investigation was process-oriented and attempted to gain an understanding of patients' experience by interviewing people at different points in their course of treatment. It is recognized, however, that the study was limited by its inability to follow patients through their entire treatment experience. Following an individual from the time of diagnosis throughout all phases of treatment would clearly provide rich data regarding the experience.

The qualitative methods utilized in the present study lead to rich, 'deep' data. Categories and themes emerging from the data could be reflective of more general social processes and may be describe the experiences of people with other chronic illnesses marked by an uncertain illness trajectory and an aggressive treatment regime. Due to the small, nonrepresentative sample in the current investigation, however, generalization, in the conventional sense, must be tentative. These findings, then, represent an important first step toward the development of a comprehensive theoretical base and need to be validated

through further research efforts.

Suggestions for Further Research

Specifically, future research should address the following questions that arise from the current study:

1. Since it is recognized that the symptoms of nausea and vomiting are highly influenced by psychological variables, could psychological interventions be useful in their prevention, management, or control? There is a growing body of research addressing this issue, particularly with reference to the utility of relaxation, hypnosis, and biofeedback techniques (Lyles et al., 1982; Scott et al., 1983). It was the researcher's observation, however, that no such programs were offered to the participants in this study. The design and evaluation of psychological interventions to decrease these distressful symptoms may prove valuable for this group of patients.

2. Further research efforts should be directed toward evaluation of nurses' effectiveness in assessing and meeting patients' informational, emotional, and physical needs. Results of this study suggest that patients depend primarily on the nursing staff as the primary health care resource. Future studies should determine if this is the case in other contexts and, if so, what nurse behaviors contribute to patient satisfaction,

3. Greater understanding of factors influencing the patient-physician relationship would also be beneficial. Research examining the impact of multi-physician

consultation may provide useful information regarding patients' satisfaction with and compliance to medical regimes. In addition, the dynamics of presenting diagnostic information should be explored.

4. The present study examined patients' responses to illness and treatment over a period of approximately two months. Although an effort was made to interview patients at different points in their course of treatment, future research should look at the coping process of individuals over their entire treatment experience. Longitudinal studies would provide answers to the question of whether patients' responses to illness and treatment vary over time. It has been speculated by some researchers that psychosocial distress following the diagnosis of cancer is temporary (Taylor, 1975). Others, such as Goldberg, Wool, Glickman, and Tull (1984) have similarly found that depressive symptomatology varies with the passage of time.

5. Future research should address the question: 'Are different coping strategies differentially successful with various problems?' This would be important to assess relative to implementation of programs aimed at teaching coping strategies.

6. Further information regarding the relationship of patients' responses to illness and a variety of background factors is required. Comparative studies should look at the relationship of variables such as age, sex, socioeconomic status, marital status, diagnosis, and

prognosis to patients' responses.

7. Findings of the current study support those of Smith et al. (1985) which identified family members as the primary source of support to patients. Research directed at exploring the impact of ovarian cancer on family role functioning and to determining the needs of these families would be beneficial.

Implications for Clinical Practice

As stated above, further studies are required to validate the findings of the current investigation. Should the results be substantiated, efforts should be made to design and implement interventions directed at problem areas identified by the informants.

1. Results of this study reinforce the importance of presenting information in a clear, unambiguous way, making sure that patients understand what they are told. Sensitivity to the particularly traumatic experience of receiving initial diagnostic information appears critical. In addition, patients expressed a need to know who was 'in charge' of their treatment plan. It would seem important for nursing and medical personnel to present information regarding the illness and treatment process more than once and to assess patients' comprehension of the information at various points. Nurse-initiated follow-up calls were greatly appreciated by patients and may serve to alleviate stress and avoid potential difficulties.

2. Patients vary both in terms of their responses and

in their needs. Individualized case conferences designed to assess these areas and plan appropriate interventions could be beneficial. Patients as well as their families should be included in the planning of coordinated multi-disciplinary care. It has been found that families have a high need for information regarding management of the patient's care (Tringali, 1986) and that their role of support-givers is primary (Smith et al., 1985).

3. It would seem that patients benefit from interaction with co-patients yet, at times, desire to be alone. Members of the health care team could explore ways in which individuals could maintain privacy and still have the opportunity to interact with others.

4. All informants in the present study reported being bothered by fatigue and decreased energy. Information and guidance related to coping with these symptoms may be useful in decreasing patients' level of distress.

5. Informants reported a number of emotional concerns including fear of the future, worry about family members, and frustration with their situation and with the health care system. They should be made aware of available psychological services and provided with the opportunity to address these and any other issues with a trained counsellor.

Conclusion

Results of the present study illustrate the complex and multi-faceted nature of cancer and its treatment and

underscore the relevance of qualitative methodology in gaining understanding of patients' experience. It is clear that if health care professionals are to provide effective psychosocial as well as physical care to cancer patients they must consider the patients' viewpoint and assure that interventions accurately reflect their needs.

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Appendix A

ALBERTA CANCER BOARD

CROSS CANCER INSTITUTE
NORTHERN ALBERTA CANCER PROGRAM

INFORMED CONSENT

Project: Coping With Cancer Treatment: Ovarian Cancer Patients' Experience of Chemotherapy

Investigator: Debra McDougall, B.Sc.N., University of Alberta

Supervisor: Ronna Jevne, Ph.D.

The purpose of the above-named study is to gain an understanding of how patients receiving chemotherapy experience and cope with their illness and treatment. This information will provide a basis for planning and implementing improvements in patient care. In addition to these long-range benefits, participants will have the opportunity to discuss their feelings and concerns in a confidential and supportive environment.

I, _____ agree to participate in the above-named project. I understand that my involvement includes private conversations with Ms. McDougall in my home as well as in the Day Care Unit of the Cross Cancer Institute. Two interviews, lasting approximately 60 to 90 minutes each, will take place in my home. In addition, I will be interviewed and observed during the course of receiving chemotherapy on two occasions at the Cross Cancer Institute. I am aware that Ms. McDougall will be observing my behaviour and interactions with other people both in the hospital and at home.

I understand that the contents of discussions with Ms. McDougall will be kept confidential and that, in the final report, all identifying information will be removed. I give permission for the interviews to be tape recorded. Transcriptions of the recorded material will be coded by number rather than name. All tapes will be destroyed at the end of the project.

I understand that I am free to withdraw from the project at any time without penalty or repurcussions. During the interviews I do not have to answer any questions or discuss any topic that I do not wish to and am free to end an interview at any time. I recognize that I may experience some emotional discomfort as a result of the interviews and am aware that, should I feel the need to talk to a counsellor, the Support Services of the Cross Cancer Institute are available to me.

I have been given the opportunity to ask questions of the researcher and am satisfied that they have been answered sufficiently. I understand that I am free to ask questions that may arise during the course of the project and can reach the investigator by leaving a message at the Day Care Unit (432-3990).

_____ participant

_____ investigator

_____ witness

_____ date

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Appendix B

Interview questions

1. How would you describe the experience of receiving chemotherapy?

2. How do you feel about being on chemotherapy? ie. what emotions do you associate with being on this treatment?

3. How does being on chemotherapy affect your life?

4. What is your understanding of your treatment, its effects and side effects?

5. How would you compare the positive and negative aspects of chemotherapy?

6. What do you do to cope with your illness and the side effects of treatment?

7. Describe the effect of your coping strategies. Which strategies are most helpful / least helpful?